

Department of Learning, Informatics, Management and Ethics; Centre for Healthcare

Ethics, Karolinska Institutet, Sweden

# Parenting children with allergy

Nina Veetnisha Gunnarsson



**Karolinska  
Institutet**

Stockholm 2011

Published by Karolinska Institutet  
ISBN 978-91-7457-593-4  
© Nina Veetnisha Gunnarsson, 2011

Printed by



[www.reproprint.se](http://www.reproprint.se)  
Gårdsvägen 4, 169 70 Solna

## Abstract

Two general questions directed the focus of this thesis: (1). What are the everyday practical and moral underpinnings of parenting children with allergy? (2). How do particularly mothers retrospectively account for and justify they are responsible parents and moral agents in the interview situation?

The overall aim was to explore the everyday practical and interactional strategies used by mothers when they are parenting children with allergy and in such contexts and relations where their parental self and identity may be at stake. The empirical data were based on interviews with parents to schoolchildren who had a food certificate at school, for diagnosed or suspected food allergy. **Study I** thus aimed at first describe what characterises the population of children with exclusion diet at school, as there was no previous knowledge about *why* children had exclusion diets and to what extend this was due to parents suspecting allergy. The study aimed specifically to describe health care contacts and diagnostic testing among the children and compare children who had respectively had not been in contact with healthcare professionals for their food-related problems. Results showed that 215 (93%) children had been in contact with healthcare professionals for any allergy, and 196 (85 %) for specifically their food related problems. Among the latter, 157 (68 %) children were doctor-diagnosed, most with a positive allergy test. Those children who had seen a doctor for the food-related problems had more complex and medically severe allergies, but overall characteristics of children's food symptoms and the reported food items were similar between the groups. **Study II** focused on the process that parents and particularly mothers engage in when trying to understand their children's symptoms and problems. The parents' narratives were reconstructed as narratives, describing the pathways parents take before they decide to seek professional medical aid as well as showing how they construct themselves as responsible parents. Before consulting health professionals the parents have often tried a range of different ways to define, control and manage their children's various problems. Parents sought medical aid when their own strategies had failed or did not fully work, but their decisions were also formed within a pre-problem context of their moral accountability as parents. **In study III** mothers accounts of healthcare encounters were explored, and the specific aim was to show how mothers used the interview situation to present, defend and sustain their identities as "good" mothers – *when* and *how* they made claims of being responsible parents (moral agency). Additional aim was attempting to explain how variations in mothers' experiences and presentations, may be formed by mothers different social belongings. The encounter outcomes were presented either as a straightforward account with healthcare as the main responsible agent or as a drawn-out process with disagreement between mothers and healthcare, resulting in different performances of moral agency. Working-class mothers portrayed themselves as dependent on healthcare expertise and made moral claims by negotiating culpability between themselves and healthcare professionals. Upper middle class mothers and mothers with higher levels of education did not generally defend and justify their actions. Instead they appealed to fulfilment of the active mother role. **Study IV** explored parents, mainly mothers, accounts of the practical and discursive strategies they use to support an ordinary life for their allergic child. This includes how they manage particularly family relations in their accounts of family responsibility and the way they control the information they give about their child to others. An ordinary life was established by making comparisons to what other children

without allergies presumably can do (and eat). Parents' support is about practical and discursive strategies used to create or uphold an ordinary life for their children. In terms of the children's food problems there is one dominant strategy the parents use, conceptualised as "the food bag strategy", where the child are given their special foods to bring when participating in different social activities. Parents work out family responsibility by for example telling moral tales, as to legitimatise and justify claims or "demands" on family members understanding and support, and family members inability to do so. Parents' practical and discursive strategies do not work in a clear-cut direction for the child's ordinary life and identity; it worked as much against as for the intention of their support.

In conclusion, mothers when parenting children with allergy, weave seemingly opposite themes and threads together in their accounts- entwining different moral positions as to show they are responsible, e.g. "good" parents.

**Keywords:** Parenting practices, motherhood, ordinary life, presentation of self, moral agency, parental responsibility, illness management, healthcare encounter, gender, social class, childhood allergy, food allergy, strategies

## List of publications

This thesis is based on the following papers:

- I. Gunnarsson, N., Marklund, B., Ahlstedt, S., Borell, L. & Nordström, G. (2005) Allergy-like conditions and health-care contacts among children with exclusion diets at school. *Scandinavian Journal of Caring Sciences*, 19 pp. 1-7
- II. Gunnarsson, N & Hydén, L-C (2009) Organizing allergy and being a “good” parent. Parents’ narratives about their children’s emerging problems. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 13 (2) pp. 157-174.
- III. Gunnarsson, N.V., Hemmingsson, H. & Hydén, L-C. *Mothers’ accounts of healthcare encounters: Negotiating culpability and fulfilling the active mother role*. Submitted.
- IV. Gunnarsson, N.V., Hydén, L-C., Borell, L. & Hemmingsson, H. *Parents support for an ordinary life for their allergic child: managing family relations and controlling information*. Submitted.

"We must put ourselves in the position of the subject who tries to find his way in this world, and we must remember, first of all, that the environment by which he is influenced and to which he adapts himself is his world, not the objective world of science."

(W.I. Thomas and F. Znaniecki)

# Contents

## *PART ONE*

<b>Prologue</b>	<b>9</b>
An empirical narrative	9
<b>1. Introduction</b>	<b>13</b>
<b>The gendered practice of parenting</b>	<b>13</b>
<b>Allergy as a childhood disease</b>	<b>13</b>
<i>Medical definitions of allergy</i>	13
<i>Food allergy diagnosis</i>	14
<i>Disease specific aspect of childhood allergy</i>	15
The lived everyday experiences of asthma and allergy	17
<i>Parental conceptualisations of allergy</i>	17
<i>Strategies of normalising asthma and allergy</i>	18
Allergy as a cultural disease highlighting individual risk	19
<i>"Allergy between the ears"</i>	20
Parent responsibility and being a "good" mother	21
The moral practice of everyday life and parenting	21
The thesis aims	22
<b>2. Methodology</b>	<b>23</b>
Food certificates: children with special diets at school	24
Sampling procedure and study participants	24
<i>Study I: The school child population and parental subjects</i>	24
<i>Study II-IV: Sampling decisions in narrative interviews</i>	25
<i>Study III: Classifications of mothers' social class</i>	26
Data Collection	27
<i>Study I: The structured telephone interviews</i>	27
<i>Study II-IV: Narrative interviews</i>	28
<i>Why narrative interviews?</i>	28
<i>The opening question and data collection procedure</i>	28
Data analysis	29
<i>Study I: Statistical analysis</i>	29
<i>Study II- III: Reconstructing chronological 'real time' storylines</i>	30
<i>Study III-IV: Narrative accounts enacting and shaping social life</i>	31
An ethical consideration	32
<b>3. Summary of the empirical studies</b>	<b>35</b>
Study I: Allergy like conditions and healthcare contacts among children with exclusion diets at school	35
Study II: Organizing allergy and being a "good parent"	36
Study III: Mothers accounts of healthcare encounters	36
Study IV: Parents support for an ordinary life	38
<b>4. Concluding discussion</b>	<b>41</b>
(1) Practical strategies shape lay knowledge of child allergy	41
(2) Gender and medical encounters	41
(3) Strategies and moral self	42

(4) The dilemma of parental control	43
(5) The 'costs' of overbearing responsibilities	44
Implications for childcare practices	45
Methodological consideration	46
<i>Method and findings mutually reinforced in narrative accounts</i>	46
<i>A note on social class explanation</i>	47
<b>Acknowledgment</b>	<b>49</b>
<b>References</b>	<b>53</b>

## ***PART TWO***

### ***Papers I-IV***



## PART ONE

### Prologue

#### An empirical narrative

I will begin this thesis with the words and accounts from two of the mothers interviewed for this thesis. My intention is to present an empirical narrative that will show what parenting children with allergies is like. The prologue may also be read as a rationale and justification for the particular focus of my thesis.

*'I think, among other things, the son who has had the most allergies, he is going to be the one who is outdoors and travels abroad the most. That is what I try to give my child in quiet knowledge; you can as long as you want to, like it is no problem. There is nothing that can prevent you just because you have this allergy, it is just that there are some things, you can think like this, for example, just because you have peanut allergy you can't travel to Indonesia because there they live only on coconut and peanuts, so I say, if you go there, you can fix it anyway. It's like, that is mine, a life approach. I try to raise my son in a positive life approach with his handicap'.*

*'It can grow out, but it should have happened by now, she is just 8 and a half years old so it is surely hard for the surrounding to understand. It is so easy to give the children this or that. Still though, milk allergy is the most common. But I have always with me, things, when it is field trips or such, then I say, you can't give this away and exchange with someone else. Then I make my special food, fruit goes well to exchange. When I make sandwiches and things, she always wants ham, it has to be cucumbers and such- don't exchange this now because maybe (child's name) can't eat it. And then the grown ups can wonder, why can't you have it. And so the whole time you have to inform, she's not supposed to eat that. It's a little difficult sometimes'.*

The first mother in the above examples looks into the future and the 'quiet knowledge' she says she tries to give her son. At the time of the interview her son had just started school; with multiple severe food allergies and asthma they have experienced emotionally trying times over the years. They had had to seek emergency care due to allergic reactions on two occasions. Nevertheless, despite the risks involved, she wanted the listener to know that her son's allergy will not hinder him from doing anything he wants. She ends her account with a finishing quote that summarises the core meaning of her parental beliefs: *'I try to raise my son in (having) a positive life approach to his handicap'*. Consequently, she instils in him the self-confidence and obviousness that he can do whatever he sets his mind to, overcoming seemingly impossible barriers for a child with multiple allergies (whose allergy had not changed much over the years).

Thus, the mother indicates something about what kind of child she wants him to be (and how she wants others to see him), and simultaneously what kind of mother/person she is, or more precisely, what kind of mother she presents herself to be. In parenting children with allergies, the parents' actions and strategies are not only about managing their children's illness, but it is as much about being able to present a parental self and identity that are morally adequate and acceptable. Being a responsible parent is firmly

connected with being able to claim a moral self. In the interview situation, thus, it becomes an inevitable aspect of parenting accounts and in the everyday practices of caring for children with chronic illnesses or disabilities. It is in fact paramount in parenthood and parenting in general, as well as in the possibilities for understanding the social practice of family life.

Both mothers present themselves as competent and assertive parents in the above accounts. It is evident that their different strategies are aimed to meet the child's needs in relation to not foremost their own private family life, but in relation and encounters with the different social situations and contexts of a social and moral everyday life. The mother in the first example shows how she, in her parenting, also has an eye on her child's future, as in making available her parental vision for the child's future by how she raises him in the present. She demonstrates how she prepares her child with multiple allergies to go out into the world and live life as fully as any other individual, even forecasting that he, 'this son', will be the one who will travel the world more than others.

In the second mothers' account, the potential 'social troubles' of having and parenting a child with allergies is also presented. The main plot of her account weaves the thread of two of the most typical parental strategies in food allergy management that has been the focus in one of the thesis studies in particular. The first strategy is how she informs others about her daughters' illness in order to make others (specifically adults) understand her child's particular needs, and how it works in the situation as a legitimate excuse for her daughters possible inadequate social behaviour. Particularly since her daughter may not always (be able to) behave in exactly the way others may expect. Making special foods for her daughter and informing others about her daughters allergy is part of her parenting support, intended to keep her child healthy but also as much to support that she may live and be like any other child.

In both these examples, the mothers portray their parenting strategies as crucial for the child's safety and social belonging, and how they see themselves as uttermost responsible for what their child may be able to do, although the second mother also indicates how other people may complicate her responsibilities. Her mothering account may also be read to conceptualise an awareness of the moral underpinnings and expectations that shape social life and interactions. In the way she constructs her account and talks about her experiences by connecting her parental actions to her daughters moral self and other peoples expectations and lack of understanding, she shows us (although not deliberately) an empirical example of how sociological theories of social control and social interaction may operate in peoples everyday lives. She presents the exchanging of foods between the children as being a mutually agreed and (ordinary) taken-for-granted childhood activity. This is why she also presumes that the other children's parents may question why her daughter does not engage in this. Thus posing a potential risk to her child's moral self, in that others may think 'badly' of her. Making these connections in her account works to substantiate and also justify her parental strategies. Without her informing others about her daughters' illness, not only is her daughters moral self potentially at risk, but so too is her 'good' mother identity, knowing that there is a likelihood that as the child's mother she will be the one potentially 'blamed' for her child's inadequate behaviour.

Apparent in both mothers' accounts is the way they present themselves and their parental actions and strategies as imperative for their children's present and future possibilities. Parenting school children with allergies, in particular, means not holding them back, which is a kind of unwritten rule that all parents in this thesis agree with. But social life may present itself with social and moral barriers that may complicate the parents' responsibilities and support.

To conclude from the above empirical opening, this thesis will contribute to knowledge in the field of illness experience in qualitative medical sociology, but with a particular focus on parenting and parenthood, and specifically, the moral underpinnings of motherhood. It relates to how parents speak about and actually parent children with allergies in their socially shared everyday life and in the interview context, for example, how they present themselves and their parental actions (and other people and their actions) in their retrospective narrative accounts.



# **1. Introduction**

## **The gendered practice of parenting**

Despite strong principles of equality in Sweden, mothers both feel and in reality have the uttermost responsibility for the children's care (Elvin-Nowak & Thomsson 2001; Kugelberg 1999). This is the typical situation in most other countries around the world (Elvin-Nowak & Thomsson 2001; Ribbens McCarthy et al. 2003; Liamputtong 2006; Miller 2007; Kugelberg 1999).

The overbearing implication of parenthood being gendered is that mothers have the uttermost responsibility for the care and well-being of their children, especially in terms of when children fall ill (Harden 2005). Still, mothers are not a homogenous group; rather they can be categorised by social belonging (class), education level, ethnicity, age and civil status, to mention a few factors. It thus becomes valuable to study both the general implications of gendered parenting and parenthood, as well as try to discern social and situational variations. The overall similarities are apparent in parenting accounts, informed seemingly by general gendered moral imperatives of parenthood, for example, the overbearing principle of putting children's needs first that seems to be a universally represented assertion that particularly mothers agree with (Ribbens McCarthy et al. 2000). Further into the thesis introduction, I will refer to some central studies about the moral underpinnings of parenthood. Examples include: Ribbens McCarthy et al. studies on parenting and step-parenting (2000, 2003); Hays (1996) on cultural contradictions of motherhood; and Millers (2005, 2007) narratives about becoming a mother; and finally, Elvin-Nowak & Thomsson (2001) and Kugelberg (1999) on working mothers in Sweden. Ribbens McCarthy et al. (2003) indicates that there are also social class differences in parenting accounts, including how middle class mothers put more emphasis on biological ties between parents and their children compared to working class mothers who explain parenting to be more socially determined.

First and foremost in this thesis, the more 'general' perspectives and moral imperatives in parenting accounts are explored. It is also mostly a mothers' perspective since the majority of the parents interviewed for this thesis are mothers. Considering that parenthood is gendered, a maternal perspective on aspects concerning the everyday care and responsibility for (ill) children also encompasses parenting practices and parenthood.

## **Allergy as a childhood disease**

### *Medical definitions of allergy*

In medical terms, the word allergy is only used for those conditions and adverse reactions that may be proven to have a known immunological origin, that is, when it is possible to medically determine by current allergy tests used in clinical and/or scientific practices (Johansson et al. 2001). The medical definition of allergy was originally developed from patients' clinical symptoms, but has continuously changed with increased biomedical knowledge of the immune system and the biological processes of allergic inflammations (as reviewed by Hed 1998). At present there are some well-

known types of immunologically induced inflammations and the most common one in childhood allergies, and one that is often conceptualised, as atopic allergy is the IgE mediated immune response.

A third specific aspect of allergy is that symptoms and adverse reactions that cannot be proven to have any known immunological mechanisms may appear very similar to the allergic manifestations. This may complicate both clinical practice as well as individuals' and parents' way of understanding and managing particularly these often loosely defined and diagnosed non-allergic problems. The biomedical knowledge of non-allergic problems is also generally scarce; consequently, the distinctions between allergic and non-allergic conditions are difficult to make in clinical practice (Ahlstedt & Murray 2006). The allergic reactions are often seen to manifest itself earlier in a child's life and are usually more severe and persistent (Sampson 1999). However, the allergic conditions being more severe and persistent does not seem to have a clear-cut relation to children's and parents' experiences of how they report them to affect their everyday life. Marklund et al. (2004), for example, showed that both adolescents (from the exclusion diet sample in our jointly conducted study I) with allergic as well as non-allergic food problems reported just as low levels of health related quality of life.

### *Food allergy diagnosis*

Food allergy compared to other allergies is specifically difficult to diagnose and many food reactions are immunologically difficult to determine, something that parents in this study express frustration with. Normally, asthma seems easier to establish and management strategies that parents may use, foremost medications, seem much more straightforward, thereby supporting the possibility of living an ordinary life with asthma (Prout et al. 1999). In contrast with medicine related asthma management, treatments of food allergy and food related problems with no known immunological origin (e.g. food-intolerance) are often limited to having parents exclude the offending food from the child's diet (Spergel & Pawlowski 2002).

Food related problems, specifically, are thus difficult to diagnose and parents often have to not only discover for themselves different remedies and strategies which may work, but they also are often required to diagnose their children's bodily symptoms and problems themselves. A common experience for many parents in this thesis population is being in a situation where neither they nor health professionals are able to determine the specific offending foods, making diagnosis unclear, and resulting in the only available remedy for food allergy being food avoidance, a seemingly challenging experience.

Food avoidance as a management strategy is seldom easy. Even in the case of a verified food allergy, particularly as certain food items, like tree nuts and peanuts may be 'hidden' in industrialised and homemade foods. Although some parents express that over the years it has become easier to avoid single 'hidden' food allergens, as manufactured foods have become labelled with a warning such as: "could contain traces of nuts and peanuts". Nevertheless, in social life homemade and baked 'social' foods brought to school outings and other family activities still pose a potential risk for hidden allergens. The risk of accidental reactions are still liable and a potential reality in parenting children with food allergies. Additionally and perhaps even more difficult,

other common offending foods in childhood allergy are milk and egg, found in many of the cooked meals and baked foods that children in Sweden commonly consume and known to like. For example, pancakes and 'Swedish' cinnamon buns, the kinds of 'ordinary' foods that are frequently offered to children at social activities in and outside of school.

### *Disease specific aspect of childhood allergy*

Biomedical explanations and definitions of allergy as a childhood disease, having become a publically well-known medical condition over at least two decades, has focused upon and spread to the public thorough media and childcare experts' advice to parents, for example, at child healthcare centres where the majority of Swedish parents regularly take their child during the first 6 years of their life (Sundelin 2000). For example, Olin Lauritzen (2004) found that medical knowledge and explanations of allergy are intertwined in parents' lay notions and experiences of their child's allergy.

Allergy as a medically defined childhood condition has certain characteristics that may be seen as disease specific. I will focus on three characteristics of allergy that I believe are significant for understanding parents' experiences and responses to their children's allergy, specifically, evident in food allergy. If parents understand their children's allergy by intertwining medical concepts and knowledge about allergy in their notions, these are thus not unimportant for parents' experiences and strategies. Nonetheless, Olin Lauritzen (2004) also found that making use of medical concepts are not the only things that parents do, which means that the medical perspective of allergy is not enough to understand the lay experiences and explanations of allergy. We will come back to this perspective later on.

The first allergy characteristic is that allergy is firmly grounded in its extremely high prevalence in the child population; thus, the familiarity it has as being a 'typical' (chronic) childhood illness of contemporary Sweden and other affluent societies. For example, in 2003 one in four children in Sweden were estimated to suffer or had suffered from an allergy (see Wickman & Lilja 2003). That is almost half the childhood population.

Secondly, allergy is highly heterogeneous, although allergy may not be publically and socially communicated in ways that represent the variations in the disease, individuals with allergy talk about their experiences in ways that show the varying character of allergy (Olin Lauritzen 2004; Roll Bennet 2006; Hansson Scherman 2002). Allergy involves many different conditions and mechanisms, and different allergies may come and go in a child's life. This aspect has been captured in the phrase 'the allergy march'. Created to describe the natural course of allergy, as in how one allergic problem may follow another in the course of a child's life. The march often starts in infancy with symptoms manifesting itself on the skin (eczema) and then with symptoms related to the gastrointestinal tract often caused by food allergens (e.g. milk and eggs), and later on with symptoms involving the respiratory tract in the form of wheezing, asthma and hay fever (Wahn 2000; Illis et al. 2001). Consequently, an allergy may involve several different organ systems such as: the skin, the upper and lower airways and the gastrointestinal tract and are, therefore, also known to mimic other illnesses.

In addition, children may be allergic or intolerant to many different substances at the same time. It is not uncommon for children to have symptoms present in two or more organ systems or suffer intolerance to more than one substance and/or food (Sampson 2004). This is also true for the child population in this thesis. Although all children have food related problems in common, the majority of the children in our sample also have other allergies and asthma, which, as to repeat, means that studying only the parents' perspective and experiences of food allergy/intolerances is seldom plausible. A child that suffers from food allergy can, for example, experience several different symptoms (Sampson 2004). A particularly acute and severe adverse reaction is anaphylaxis, which results in symptoms affecting all of the above areas, including blood circulation (Sicherer 2002; Moneret-Vautrin et al. 2005). Among the children with special diets at school in this thesis, the most common offending foods reported by the parents included tree nuts and peanuts. Nowadays, peanuts are maybe the most commonly reported food resulting in severe symptoms (Moneret-Vautrin et al. 2005).

Considering these characteristics of allergy, it is not surprising that parents often have a hard time knowing exactly how their child will react to certain foods. For example, in terms of peanuts most children in this thesis and children with allergies in general have had their allergy confirmed often through a representative IgE antibody test in the blood at such an early age when children usually have not eaten peanuts due to the risk of choking. To further complicate the matter, determining peanut allergy is tricky, as the appearance of sensitisation in the blood is not always linked in a clear-cut way with a clinical manifestation (symptoms) of peanut allergy at such an early age (Nicolaou et al. 2010).

A third aspect known to further complicate children's allergy representation is that reactions and symptoms vary in severity and manifestation at different times, ages and places, as well as between individuals. Sometimes a child may tolerate the offending food and sometimes he/she may not, or the child may experience a mild reaction on one occasion, followed by a more severe reaction several days later (for example, when the child also presents with some kind of acute infection), especially relevant in food allergy (Sampson 2004; Sicherer 2002).

Allergies often change over a child's lifetime; different new allergies can develop and others may disappear (as in the allergy march). It is known that children often outgrow particular food allergies from childhood prior to starting school, on the other hand there are also indications that food allergy may persist up to school age (Sicherer 2002). This could be seen in most of the children in the thesis population, as it partly explains why they had special diets at school. These aspects may also be especially important in the Swedish context, where (cooked) midday meals are served at school.

All parents interviewed for this thesis had at least one or more children with food allergies (defined in this thesis as having symptoms manifesting itself on the skin, upper or lower airways or gastro-intestinal tract upon exposure), mostly diagnosed but occasionally parent defined. In addition, most children also had other allergies and asthma. At the time of the interviews all children were in their school years and had special diets at school. Most studies about individuals' and parents' experiences and responses to allergies have focused particularly on asthma, and less about allergy in general and even less experiences related to food allergy. Not being able to eat what



others eat in ones sociocultural context has special connotations, as foods are a crucial part of social life. Food is not only materially necessary; it is above all a powerful social integrator and deliverer of fellowship and social belonging (Douglas 1992). Many children suffer from multiple allergies rather than a single one, and it is often difficult for parents to discern what problems are related to which type of allergy. The focus of this thesis is thus not merely on food allergy. Still, several of the examples accounted for by parents in this thesis are connected to food allergies, which may give important insight into the specific and tricky aspects of parenting children with food allergies.

### **The lived everyday experiences of asthma and allergy**

From the medical background and knowledge about allergies, it is known that it is a highly changeable and heterogeneous childhood diseases with food allergies, in particular, being quite difficult to define, diagnose and treat. The disease trajectory of allergies is still not fully understood; however, knowledge about the immunological and clinical expressions still enables healthcare practitioners to offer help to many of the affected children and their parents, especially in terms of asthma. However, there are still other sides of allergy that we continue to know less about. For example, how allergy is understood, explained and managed in everyday life- focused upon in this thesis. As most children with an allergy are often diagnosed at an early age, usually before the age of two, it means that it is foremost the parents' work, particularly the mothers, to make sense of and manage the allergy in everyday life.

The everyday perspectives from individuals and families living with a particular chronic illness are important, not only because lay people are known to understand and respond to illness in a different way than healthcare professionals and the medically explained categories (see Mishler 1984; Radley 1994), but also because people who are ill do not simply have a disease and because they are not simply patients. People construct their understanding of illnesses through their lived everyday knowledge and bodily experience of their (social) world and self (Radley 1994; Bury 1997). For example, in talks and narratives of the lived illness experiences people may show how illnesses function for them, as to help them understand and adapt to their problems within the sociocultural contexts of their lives (Hydén & Mishler 1999).

When focusing on individuals and carers' interview accounts of illness experiences and the consequences of illness in different everyday situations, an aspect that may emerge is how the onset and persistence of symptoms disrupt the flow of normal everyday living and create a growing uncertainty in individuals' and families' lives (Charmaz 1993; Bury 1997). Chronic illnesses such as asthma and allergy may in different ways be potentially disabling; moreover, self-care activities and different daily routines at home, at work and in school may become problematic (Bury 1991, 1997; Gabe et al. 2000).

### *Parental conceptualisations of allergy*

In her study, Olin Lauritzen (2004) shows how parents conceptualised their understanding of their children's allergy by revealing a complex pattern that intertwines medical explanations and the parents' own experiences of allergic conditions (Olin

Lauritzen 2004; see also Roll Bennet 2006). Parents reflected on different causes of their children's allergies that they referred to as "shared or generally known" (Olin Lauritzen 2004; Roll Bennet 2006), for example, causes connected with the physical environments such as bad or polluted air, chemicals and housing, elements of the families lifestyle such as having pets at home, smoking and different types of foods that should be avoided (Olin Lauritzen 2004; Roll Bennet 2006). Additionally, parents believed that allergy was caused by a combination of different causes and that these were individual (Olin Lauritzen 2004). Parents' understanding was often connected to what they believed *they could do* in order to influence the children's problems (Roll Bennet 2006).

Specifically, three different explanatory narratives were used by the parents to understand children's allergy (Olin Lauritzen 2004), at a time when their children's allergies had just been diagnosed. They either talked about their children's allergies as something temporary, saying that the child had been ill but was now healthy again. These parents normally did not view their children as allergic. The most common explanation found among parents was that the child was perceived as healthy in general, but having episodes of illness (the above explanations may be considered in connection with the characteristics of the allergic conditions as described earlier). These parents stated that they "did not know" if the child had an allergy. Finally, other parents were convinced that their child suffered from an allergic condition. These parents had either accepted a previous allergy diagnosis or those with a non-diagnosed child who had been convinced from the beginning that the child was going to be allergic, usually the parents who had allergies themselves (Olin Lauritzen 2004).

### *Strategies of normalising asthma and allergy*

In managing chronic illnesses individuals and their families are known to use both short- and long-term management strategies, often as a way to limit the practical and social consequences of the illness (Radley 1994; Bury 1997). The different *adaptations* that people make in response to illnesses are a way for the ill to bridge self, identity and social action (Bury 1982; Charmaz 1993). Children with asthma and allergy, like other chronically ill individuals and their caregivers, may specifically work to minimise the affect the illness has on their everyday lives by trying to reconstruct a normal life, a process known as a *normalisation* (James 1993; Adams et al. 1997; Bury 1997; Prout et al. 1999; Hansson-Scherman et al. 2002; Roll Bennett 2006).

Prout et al. (1999) found that children with asthma did not present their illnesses as being very problematic, despite being unable to participate in physical and social activities. It was considered 'normal' for them to sneeze and cough, and the children still thought of themselves as feeling well. Symptoms like wheezing and coughing were also experienced as quite normal occurrences by the parents and symptoms were not always directly associated with asthma, although all children had received an asthma diagnosis (Prout et al. 1999).

Furthermore, children and their parents were primarily concerned with maintaining and producing a sense of *ordinariness* in their everyday lives (Prout et al. 1999). Strategies like removal or avoidance that included getting rid of furred animals or changing carpets were not used much. Both the children and the parents were more prone to using asthma medication in managing asthma problems. The authors argue

that asthma medications were more useful in keeping up the ordinariness of the families' everyday lives because taking medication did not affect the families' lives as much as lifestyle changes did. However, Roll Bennet (2006) found the opposite in terms of parents who had children with eczema and allergy. They used several removal strategies, like that of removing certain foods from the child's diet.

To maintain a normal or ordinary life is also closely connected to people's identities (Radley 1994). Adults with asthma may reject and distance themselves from their asthma or redefine their social asthma identity (Adams et al. 1997; Hansson-Scherman et al. 2002). They did so especially when their perception of being asthmatic yielded a strong negative and stigmatising mark. In particular, they denied or distanced themselves from the asthmatic identity when and if it was perceived as being a threat to their self-image.

In a Swedish ethnographic dissertation, Hansson (2007) focuses on young adults (15-30 years of age) with asthma and how they try to manage and to live an everyday life as much as possible like that of their peers. He argues that these young individuals with asthma do not always construct themselves as independent subjects or primarily choose to take on responsibility for their illness in the way healthcare and the pharmaceutical company's assume them to do. Rather, they often choose to hide signs of their asthma that would risk objectifying them, which meant their actions were foremost controlled by their relations and interactions in the outside world.

### **Allergy as a cultural disease highlighting individual risk**

There is yet another perspective to allergy that neither the medical disease perspective nor the individual/parent everyday illness perspective have focused on. Eriksson & Qvarsell (2003) conceptualises allergy as a *cultural disease* that goes beyond being a medically definable disease and a common chronic illness and a public health problem. A cultural disease is related to the *sickness* perspective, which Sachs (1997) describes it as the (socially) communicated meaning of the lived illness and medical disease (as in how people are labelled as ill in a certain society and social contexts).

Eriksson & Qvarsell (2003) point out that (everyday) life is full of risks and that responsibilities (and blame) for risks and risk elimination and control is placed on the individual, which is a particular aspect of western societies (see Douglas 1992). Individual responsibility is based upon enlightening and educating people about the risks of living, assuming that individuals (as parents) have the resources to make the 'right' decisions to reduce or control risks to their health and their lives (and their children's) (Eriksson & Qvarsell 2003). There is, thus, a high possibility that the children's illnesses in such contexts are at least indirectly 'blamed' on the parents.

Allergy is a medically and publically conceptualised lifestyle illness, often discussed and understood as an example of an illness that reminds us about the 'modern' everyday risks. The risk of allergy is routinely communicated to parents through child healthcare settings and expert advice, media and other public and social arenas. However, the risk discourse of food and food allergy is also contested and are communicated in biomedical and clinical settings as well as in organisations and institutions through demarcating

what is a 'true food allergy', or 'food allergy' and 'food intolerance' (see Nettleton et al. 2009).

### "Allergy between the ears"

Besides the risk discourse of allergy, there is yet another socially communicated meaning of allergy connected with the knowledge about the large discrepancy in prevalence between a medically verified food allergy and a parent/subjective perceived food allergy (Sampson 1999; Björkstén 2001), also connected with a divide between that of 'true food allergy' and food allergy. True food allergy means having a verified clinical and immunological proven food allergy (for example, peanut allergy), determined by what is considered 'the gold standard' of food allergy diagnosis (although used mainly in research), the double blind placebo-controlled oral food challenge (see Clover 2006).

The contested meanings of food allergy when perceived and interpreted by the public, may lead to food allergy becoming further questioned in terms of its legitimacy as a 'real' medical condition. For example, individuals may contest whether different foods can really cause illness and such potential threat to a person's health (or life), as is actually the case for many children with food allergies (considering that they often have other allergies and asthma). The discourse of food allergy as being 'real' or 'imagined', also seemingly communicated to individuals in clinical practice (see Nettleton et al. 2009) are additionally put forth in psychologically oriented research. For example, in studies exploring or discussing other potential reasons that make people overestimate foods as the cause of their problems. From the medical perspective, the expression 'true food allergy' as mentioned above, captures the same underlying meaning (see Nettleton et al. 2009). In carrying out the first study in this thesis, my colleague Birgitta Marklund and I also encountered from time to time a sceptical and mocking attitude from people concerning food allergy, as illuminated in the expression: "allergy between the ears" (Shepard 2006). In psychologically oriented research, a connection between over reporting of foods as the cause of symptoms and psychiatric illnesses in women (Knibb et al. 1999) as well as college students' personalities (Bell et al. 1993) has been put forth. Although it is known that stress can trigger the immune system, when explanations of this sort are socially communicated it easily leads to a 'blaming the victim' discourse that puts moral weight on individuals, especially so on parents.

The individualised and psychologised discourses embedded in the principles of individual responsibility of health and illness (Michailakis & Schirmer 2010) may have a catch-22 effect in the everyday lives of individuals and carers trying to manage and control their or their children's illnesses. Because on the one hand, individuals are expected to take on responsibility for their health, as in food allergy and food intolerance, where diagnosis are often dependent on the parents making their own diagnosis of the children's food problems. But when individuals (as parents) do take on such responsibility, they are on the other hand potentially 'blamed' for it, and may in the process risk being labelled as psychologically unhealthy or being a certain kind of (anxious) person (or risk being labelled an overanxious parent).

## **Parent responsibility and being a ‘good’ mother**

To control and manage potential risks that children may encounter in their everyday life is the work of parents, and to repeat in terms of gendered parenting, particularly that of mothers. Parents are in principle responsible for everything that concerns their child, in terms of the child’s care, upbringing and well-being. Being a parent means that you have other people’s eyes on you, or metaphorically speaking, the eyes of ‘society’ on you, thus ensuring that you perform your parenting duties the way you ‘should’ that is, the culturally agreed and expected way. As children are understood to be fully dependent upon their parents and constructed outside of moral agency by their parents (Ribbens McCarthy et al. 2000) (and the state), to be a parent and living a family life means being in a place where your moral identity is crucially at stake (Finch 1989; Ribbens McCarthy et al. 2000). Although it seems that fathers have more possibilities to ‘escape’ and through other social means withstand the overbearing moral imperative of ‘putting the children’s needs first’, it seems to be a general parenthood assertion that mothers, in particular, agree to (Ribbens McCarthy et al. 2000).

The imperative of putting children’s needs first may be implicated in what Brown et al. (1997:198) concludes from interviewing 90 mothers about what “good mothering” entails, which is that the most striking aspect in mothers accounts “is the heavy burden put on the mothers of attempting to reconcile persuasive beliefs about being a good mother, with the many competing demands in women’s lives”.

When a child falls ill, parents’ actions (and non-actions) may become even more socially scrutinised as there are also social expectations on what parents should do and how they should act when their children fall ill. Moreover, social control in terms of medical and healthcare expert surveillance may present itself as a heightened unspoken as well as outspoken moral pressure on parents and their parenting, perhaps leading them to have to even more feverishly show themselves to be good and responsible parents. Perhaps the relationship between parents having the uttermost responsibility for their child, but at the same time having to justify they are good parents and defend how they parent their child may be explained by what Murphy (2003) states as a paradox of family life in contemporary liberal states. Specifically, on the one hand, should the state respect the autonomy of individuals and families, and on the other hand, is there also a concern to influence and regulate social and economic life, thus, involving the seemingly private affairs of family life (Rose 1992; Murphy 2003). For example, in terms of deciding and regulating what children need and should eat (Murphy 2003).

Managing allergy is thus inevitable, just as much as parenthood and parent responsibility. A potentially ‘bad’ mother or a mother who has not successfully shown herself to be a ‘good’ mother in situations (e.g. healthcare encounters) where her moral identity may be at stake, may not be able to claim a moral self (Ribbens McCarthy et al. 2003; Liamputtong 2006).

## **The moral practice of everyday life and parenting**

The point of departure of this thesis is that we, as social members, have a taken-for-granted knowledge of our everyday lives, which we construct and maintain in

interactions and relations with each other (Bergman & Luckman 1998). Thus, the normalisation strategies used by people to reject or conceal a diagnosis or allergy identity, or the parents' use of medication to maintain a sense of 'ordinariness' in their children's lives, are some examples of the lived adaptations people may make in response to chronic illnesses. However, studies about such normalisation strategies described before, tend to explore these lived experiences of body and self and parental strategies as if they were private everyday experiences made in a social vacuum. But, everyday life is intrinsically social and moral, and an important aspect not investigated much in the mentioned studies is how parents presents themselves as a 'moral' agent, although this is crucial for any member of a particular society and social group (Goffman 1959,1968; Sayer 2005), but particularly so for parents who are held responsible not only for the outcomes of their own lives, but also their children's.

Hence, in connection with the above, two overall questions about parenting children with allergies may be formulated: 1) What is the everyday practical and moral underpinnings of parenting children with allergies? 2) How do parents retrospectively account for and justify that they are responsible parents and moral agents in the interview situation?

### **The thesis aims**

The overall aim of this thesis is to explore the everyday practical and interactional strategies used by mothers in parenting children with allergies, and in such contexts and relations where their parental self and identity may be at stake.

The specific aims of the study are:

- a) To describe health care contacts and diagnostic testing among school children with exclusionary diets, and compare the magnitudes of allergy-like conditions among those children who had versus those who had not consulted health care professionals for their food-related problems (study I).
- b) To focus on the social problem-solving processes that parents and particularly mothers engage in when trying to understand their children's symptoms and problems, and in accounting for their parenthood by analysing the parents' narratives about how they recognise, interpret and respond to their children's bodily problems before seeking professional healthcare aid (study II).
- c) To explore mothers' accounts of healthcare encounters where questions about their children's (allergy) problems are in focus. It aims particularly to show how mothers use the interview situation to present, defend and sustain their identities as 'good' mothers – *when* and *how* they make claims of being responsible parents (moral agency) (study III).
- d) To explore parents, mainly mothers', accounts of the practical and discursive strategies they use to support an ordinary life for their allergic child. This includes how they manage family relations, in particular, in their accounts of family responsibility and the way they control the information they give about their child to others (study IV).

## 2. Methodology

### Food certificates: children with special diets at school

The empirical data for this thesis are based on interviews with parents of children, who either have a doctor's diagnosed/medically verified or a suspected food allergy. In Swedish schools, the children are served a cooked mid-day meal, which means that children may, for a number of reasons need special meals at school. The most common reason for having special meals at school is because of food allergies/intolerance.

The sample of children and their parents come from a municipality in a southern suburb of Stockholm. During the start of the data collection in 2001, this community had a special awareness of allergy. This was connected to a collaboration the municipality had with an allergy researcher at the Karolinska Institutet, and this was also a contributing factor as to why this community was chosen as the location to collect data from. Additionally, because the children's exclusion diets and special meals were organised by the public schools by means of specific *food certificates*, it made it both possible as well as more manageable to collect and systematise data about the parent perspective, of both a medically verified and a parent suspected food allergy. Consequently, we had access to a wider population of children with allergies that we suspected would include children who did not belong to a clinical population, for example, children whose parents had not taken them to see a doctor or who had not been diagnosed by a doctor.

As the population was institutionally organised, it means that it was not an 'open' population. However, at the time of the data sampling there was no request from the schools that the children had to have a medical certificate to get special meals. In fact, this sampling means the possible biases of selecting parents through, for example, patient organisations have been reduced, as the parents in our sample were not contacted because they had themselves initiated being part of our study.

The children's food certificates included information about the different reasons as to why children had special meals at school and what foods the children had to avoid. Different known allergens such as: egg, milk, soy and fish were specified in the certificates, and for example, pork for religious reasons. It was the school nurses who wrote and administrated the certificates usually based upon the parents' information (in some cases, the adolescents'). The nurses then forwarded the food certificates to the school kitchen where school meals were prepared.

Study I in this thesis was carried out jointly and equally by both authors (NG and BM), and was aimed to describe the specific characteristics of the population of children with exclusion diet at school. There was no previous knowledge about *why* children had exclusion diets and to what extent this was due to parents suspecting an allergy. As such, we wanted to get an overall picture of the children's illness and medical histories, the characteristics and magnitude of their allergy problems, to what extent parents felt it necessary to seek professional medical aid for their food-related problems and if and how they had been diagnosed. The first study was an important starting point for gathering information about the children's problems from the parent perspective, and important background understanding of this population that guided what kinds of

questions should be explored more in depth and the strategic sampling for the interview studies that makes up the main body of my thesis.

## **Sampling procedure and study participants**

### *Study I: The school child population and parental subjects*

Consent to collect the food certificates were obtained from the municipality and an ethical committee at Karolinska Institutet. All food certificates that school children had in the last quarter-year of 2001 were coded by the diet consultant and then collected by the two authors (NG & MB). In all, 7,216 school children were registered at seventeen public schools in the municipality. At the time of the study, 602 school children had a food certificate, thus, 8% of all children attending these public schools. Among all children with food certificates, there were 305 children who had an exclusion diet for reasons other than allergy, such as religious reasons, vegetarianism or other chronic illnesses (e.g. diabetes and celiac disease). Another six food certificates stated that the child merely had a dislike for the food in question. Hence, the remaining 291 food certificates indicated the children, who had a food certificate issued because of a parent or self-reported food allergy.

Due to the fact that the food certificates changed every school term, we soon discovered when collecting the certificates that the schools had difficulty in keeping them accurate and up to date. From the 291 food certificates indicating food allergies, information pertaining to home addresses or phone numbers was missing for approximately seventeen children. In the end, parents of 274 children were contacted.

As an initial step, the parents received a letter with information about the study. They were then informed that we would contact them by telephone within two weeks. The parents were, however, encouraged in the letter to phone or to return an attached note if they did not want to be contacted. In all, thirteen parents declined participation, either by the written note or mostly by a telephone call. Another thirty-one children were excluded because the parents told us that their children no longer had food restrictions at school. The schools had simply failed to remove their certificates for the upcoming school term. Thus, the final sample of children who had exclusion diets at school in November 2001 because of suspected food allergy comprised 230 children. Some of the 230 children were siblings and finally, 215 parents were selected to participate in the first study. Only one parent in each family was asked.

The majority of the participants were mothers (80%), due to the fact that most fathers answering our phone call clearly declared that it was the mothers, who were most knowledgeable about their children's allergy. The fathers thus commonly handed the telephone over to the mothers, not uncommonly before we even had had the chance to ask them to participate. Since this was a common pattern among the fathers, it explains the gender distribution among the participating parents. This is also the typical gendered distribution of childcare and parent responsibilities among Swedish parents in general (Elvin-Nowak & Thomsson 2001; Kugelberg 1999).

All parents interviewed understood and spoke Swedish (93% was Swedish born). The majority of parents had attended secondary school (50%) or had a university degree



(39%), which follows the educational level of the whole municipality in 2010, and the national statistics

(<http://www.tyreso.se/upload/Om%20kommunen/Statistik/Tyresö%20i%20siffror/2011/Engelska%20html/utbe.html>.)

### *Studies II-IV: Sampling decisions in narrative interviews*

In Studies II-IV, a smaller and strategic sample (Patton 1990) of nineteen parents was selected from the whole group of parents of children with special diet at school. According to Kvale (1997), ten to fifteen respondents are customary in qualitative interview studies. Nineteen parents were thus considered to be sufficient for the purpose of this study, as analysing narratives in depth are time consuming and difficult to perform with larger numbers of participants.

The selection of parents was made from the information parents gave about their children's emerging problems in Study I. The inclusions were made from a variation strategy (see Patton 1990, Conrad 1990), and made among dimensions primarily related to the children's medical and illness histories, but also to some social characteristics of the parents. These reflected to some extent the diversity of the whole population of children with exclusion diets and their parents. Variation sampling enhances the possibility of making generalisations based on context similarities and/or on conceptual and theoretical patterns, which means that selecting a varied data material is significant for being able to develop a conceptualised and theoretical understanding of a particular process and contextualised experiences (Larsson 2009).

Sample diversity was made for this thesis regarding children's age, age at onset of symptoms, type and severity of different food-related symptoms, diagnosis and diagnostic results, as well as the presence of other allergic conditions, such as asthma, eczema and hay fever. However, the children's problems had to be perceived as significant by the parents. For example, one parent who stated that the child had reacted only once to strawberries was excluded. Selecting this parent would have obscured the possibility of making valid comparisons (and conceptual generalisations). Strategically, the rationale for not including this parent was that the child's problem could not be considered comparable to the other children with food allergy/intolerances who often also had one or two more allergies.

Three parents were specifically selected because during previous telephone interviews they had reported that they had not consulted health professionals for their children's allergy-related problems. Five families had more than one child with an allergy, but not all siblings had a food certificate at school. Two of these children were not part of the food certificate study population, in one case because the child did not have a special diet at school and in the other case because the child had finished school.

According to the statements made by the children's parents during the telephone interviews, twenty-one of the twenty-six children were doctor-diagnosed, and fifteen had tested positive with some kind of allergy at least once in their lives. In terms of having contacted healthcare, those parents who had reported that they had not consulted healthcare had in fact done so, but for other allergies such as pet, pollen or asthma, and not specifically for the children's food related problems. Most children thus

had other allergies besides their food-related problems. Sixteen children had asthma, fourteen children suffered from eczema and fourteen from hay fever (pet/pollen). Eleven children had all of these problems – asthma, food allergy and eczema or hay fever. The children's (and one young adult) ages were between seven and twenty-three at the time when the interviews were carried out and the mean age when the first initial problems emerged was 1.2 years, with an age range of newborn up to seven years (only one child at seven years).

All of the participating parents perceived themselves to have the uttermost responsibility for the child's allergy. The participating parents in this sample were also mainly mothers (eighteen mothers and one father), for the same reasons explained in the first study. Six parents were single parents and three of non-Swedish background (USA, England and Chile). A letter was sent out to the selected parents to inform them about the project, also stating that they were going to receive a telephone call within two weeks timeframe. Previously, in the first study, all 215 parents were asked at the end of each telephone interview if they could consider participating in other, but separate and different studies that we were also planning to conduct. The vast majority of the parents answered they could consider doing so.

Seven parents had university degrees (one was a student in her final year). Another parent had taken single university courses in English and literature. Two of the mothers worked as alternative therapists in complementary and alternative medicine (CAM). At the time of the interviews, the parents' ages ranged from thirty-three to forty-five years of age.

### *Study III: Classification of mothers' social class*

In Study III, we specifically included only the mothers' accounts; a decision made from the knowledge gained from previous studies (and Study I), namely, that it is mostly the mothers who take on responsibility for children (Kugelberg 1999; Elvin-Nowak & Thomsson 2001) and is thus the parent who takes the children to see a doctor (Harden 2005). Additionally, as widespread beliefs in the construction of the good mother is that women's mothering abilities are naturally given and an essential part of being a woman, there is thus a stronger moral accountability put on mothers in comparison to the fathers (Hays 1996; Ribbens McCarthy et al. 2000). In the construction of the good mother there is also an acceptance of the mothers' need for expert medical guidance in reproduction, childcare and mothering practices (Hays 1996; Miller 2007).

In Study III, an additional focus was to analyse the mothers' different performances of moral agency, in particular, as connected with their social group belonging. It was considered possible to account for social class as a contributing factor for the differences that were apparent in mothers' experiences of, specifically, initial healthcare encounters. For example, how they narratively positioned themselves in relation to healthcare professionals in their accounts and the interview context.

Social class was determined by the mothers' occupation, following the Swedish socioeconomic classification system (SEI) ([http://www.scb.se/statistik/\\_publikationer/OV9999\\_1982A01\\_BR\\_X11ÖP8204.pdf](http://www.scb.se/statistik/_publikationer/OV9999_1982A01_BR_X11ÖP8204.pdf)), and additionally their education level. Another social dimension that guided the

classification of the mothers' social belonging was where in the municipality the mothers lived. There are three main living areas in the municipality, which are divided in terms of the kind of housing arrangements that dominate in these different areas. One area with mainly (purchased) detached houses represents where mostly upper (middle) class and some middle class mothers lived. The second area with mainly semi-detached housings (but also detached) where mainly middle class mothers lived, and the last area in the centre of the municipality with mainly apartments (and semi-detached houses) where most working class mothers and most single (middle class) parent mothers lived.

The class distinctions in Study III were intended to merely account for relational differences in mainly cultural (educational) capital (see Bourdieu 1977) between the mothers in this study (e.g. meaning some mothers had more cultural capital than others). As such, the classifications are not to be read as representing a general Swedish upper middle, middle- and working class mother definition. Most mothers had a middle class background (lower and middle class), four mothers from upper (middle) class, and four mothers from working class (lower and upper working class). Six mothers had a university degree (one being the student as mentioned before). The distinction in cultural capital between the mothers is generally most evident between the upper (middle) class and working class mothers. It was not possible from the available data to find any nuanced dimensional differences between the mothers within the class definitions.

## **Data Collection**

### *Study I: The structured telephone interviews*

The data collection for Study I was made initially through telephone interviews with parents of the whole population of children with special diets. Later on, the interviews were also complemented with a postal questionnaire. The postal questionnaire had questions similar to those of a large epidemiological study about asthma and allergy, called the ISAAC study (see Asher & Weiland 1998). The questionnaire followed up on questions about the allergic conditions, hay fever, asthma and eczema, and different food items that were missed in the telephone interviews that were important to know about in order to gain a more complete picture of the children's allergy history and food-related problems. In the telephone interviews, the parents were asked to respond separately for each child, and a postal questionnaire was also sent for each child. The interviews were carried out by both authors (NG) and (BM), equally and randomly. A structured interview schedule that included twenty-one different questions was used. The answers were recorded during the interviews in different response categories (again according to ISAAC; Asher & Weiland 1998). Before doing the interviews we agreed on how to ask the questions, as this is important in order to keep the interviews as similar as possible (Rosengren & Arvidson 1992). For instance, there was an agreement that the response alternatives should be specified to the parents only if they did not know what to respond.

The study started out as a descriptive survey. The decision to use telephone interviews was made because of the known methodological difficulties about, firstly, how to formulate written questions so that respondents understand them as intended (Rosengren & Arvidson 1992). With telephone interviews, questions could be clarified

during the interviews. A second reason for doing telephone interviews was related to the often, poor response rate when doing postal survey enquiries. We regarded it as much more likely that the parents would participate if they were contacted by us in person. Thus, in our case the response rate was 94% for the interviews. Eighty per cent of the parents returned the postal questionnaire, whereas we contacted the other parents again and asked the questions over the phone.

### *Studies II-IV: Narrative interviews*

The data to the qualitative studies II- IV were based on the narrative inspired interviews, carried out in the year 2002 in either the parents' homes or at their workplaces. In these interviews the purpose was to, as much as possible, let the parents speak 'freely' about a few more broad but previously formulated questions. The questions covered the following overall areas: 1) how parents understand and respond to their children's symptoms and behaviours as an illness- allergy (the discovery) 2) what happened when parents sought healthcare help and how they experienced foremost the initial encounters with healthcare professionals when an explanation and diagnosis of the child's bodily problems were in focus and 3) how the child's allergy had impacted on the child's and the families everyday life, with a focus on what parents had done to manage, for example, potential consequences of the child's allergy.

### *Why narrative interviews?*

Mishler's (1986) view of interviews as a discourse between two speakers was the starting point when deciding to do narrative interviews. Meaning that the interviewer and the interviewee jointly create the meaning of what is said in the interview situation. It was also a decision made from wanting to explore and understand social processes. The first narrative study focused on how parents recognised and responded to their children's emerging problems in everyday life, which evidently meant identifying different episodes, events, actions and factual contents making up a process of help seeking. Through stories, people structure, organise and make sense of their everyday (socially shared) world; furthermore, narratives carry social meaning and cultural values that, for example, "encode, implicitly or explicitly, standards against which actions of the characters can be judged" (Pentland 1999:712). A third aspect that was considered at the time was how to deal with the interview retrospectivity. In this thesis, the 'real time' focuses of the different studies were significantly distant from the time of the data collection. But as is evident, in any interview accounts, it is how people explain and evaluate the past from the present. That people's accounts represent what 'actually' happened is not the kind of knowledge we gain from interviews (Riessman 2008), especially when the intention is to understand and conceptualise mothers' parenting accounts and the moral dimensions of parenthood.

### *The opening question and data collection procedure*

The first open question that was put at the beginning of each interview was the following: "could you tell me how you discovered that your child was hypersensitive?" Most parents responded to that question by telling a story that included: (1) how, when and where the problems started, (2) and what happened, (3) mentioning different

people that were present and what they did/said, (4) what the parents themselves did and how they felt/thought and (5) their conclusions and evaluation of the events and actions included in the story. The stories were different in structure but had more or less all of the above features in them. Although the opening question had a direct link to the aim of Study II, often parents followed the first question with their story about what happened when they sought healthcare. Moreover, they simultaneously inflicted their present situation and current strategies used as they made sense of the past.

The above initial question kick-started the parents into telling their stories in different and individual ways (Mishler 1999). For example, one mother began her story at pregnancy; others began by providing details about the children's symptoms and yet others with a specific 'discovery event', which could be very vividly remembered and quite dramatic. Some of these first stories were extensive, some were shorter, and the subsequent dialogue often concentrated on these first told events and actions. Most parents were interviewed on two occasions, but four parents were interviewed just once. Three of the parents, interviewed just once, were chosen to complement the first selected parents. In the first study, these mothers had given the information that they had not had any contact with the healthcare professionals regarding the child's food related problems. Since it was the last interviews and what these mothers shared had many similarities with the other parents' stories, it was decided that it would be enough to interview them only once, in order to catch the core variations of their stories (Mishler 1986).

Several attempts were made to schedule a second interview with the fourth parent. However, meetings were re-scheduled and missed, so in the end there was a short second interview conducted over the phone, in an attempt to fill in the gaps from the first interview. The first interviews lasted between 45 min. to 1-½ hours. The second interviews were often shorter, between 30 min to 1 hour.

Thereafter, the interviews were recorded and transcribed verbatim. Certain interview passages were later corrected and transcribed more linguistically, detailed with pauses, speech overlap and so on. The ambition of the narrative analysis was, thus, to capture the forms and structures of the parents' experiences and why they chose to tell about their experiences in a certain way (Riessman 2008). Some information was written down by hand, for example, when the parents informed about things after the tape recorder had been turned off. The parents' tone of voice, and voice changes and other more visual aspects of the interview discourse were occasionally analysed, especially when such discourse devices were clearly used to further emphasise the meaning of what the parent said. Such expressive devices were analysed, particularly in Studies III and IV.

## **Data analysis**

### *Study I: Statistical analysis*

The analysis of the data in Study I was made by descriptive statistics and cross-tabulation for comparisons between groups. To investigate if there were any differences in proportions between the groups of children who had consulted healthcare and those

who had not in terms of the extent of their food-related problems and other allergies, the Fisher's exact test (two-sided) was used. The Fisher's exact test gives more accurate figures when one or both groups are small. The Mann-Whitney U test was used to determine differences regarding age at onset of food-related problems between the same groups. A statistically significant difference was considered to be at  $<0.05$  p- value.

### *Studies II & III: Reconstructing chronological 'real-time' storylines*

The narrative analysis employed primarily in Study II but also partly in Study III was initially inspired by Mishler's studies (1995, 1999). First, the interviews were analysed by reconstructing the parents' stories and their accounts into a 'real-time' chronological order. A storyline was thus reconstructed in this way, by retracing past events and actions talked about by the parents and placing them in a sequential order. Each event or action was viewed as contingent upon the other, one event led to certain actions and these actions in turn led to certain outcomes and so forth (Mishler 1995, 1999). Second, the individual parents' storylines were compared to each other, to find variations and similarities between them. Third, a common pathway was constructed to conceptualise a general process, including the 'discovery' of a child allergy (Study II) that led up to the time when parents sought medical help.

The specific events and actions that each parent talked about were visually organised by hand in a timeline on a sheet of paper, and showed the chronological order of events in parents' stories, including what action parents took in response and so on. For example, one timeline started when the child started behaving differently or showed visible symptoms at about one year of age, and ended with the diagnosis of milk protein allergy at thirteen years of age. In between these times several events and actions had taken place. Parents emphasised some actions and events more than others, and in this way they indicated what they considered to be important. These timelines were made up as to organise and mirror the parents' individual storylines. As a result, the storyline could cover several years or only a few years depending on how quickly a satisfactory problem resolution (e.g. diagnosis and remedy) was obtained.

In the final analytical step, for each of the parents, the individual storyline were compared with each other and a common process was constructed that involved different 'time nodes', which were the same for all parents. The findings in Study II 'represent the period up to the time when parents decided to seek medical aid, although the storylines of parents and their children's lives with allergies goes beyond this. The mothers' experiences of what had happened in interactions with healthcare professional (Study III) were formulated as part of the initial process in Study II. However, in order to make a deeper and more contextualised analysis of the mothers' healthcare accounts, we decided to construct two separate articles. Thus, exploring more thoroughly the mothers' moral identity work in relation to the healthcare encounter, a topic that was only briefly mentioned in Study II and in my licentiate thesis (Gunnarsson 2007).

The reconstructed narratives are not to be viewed as a correct historical reconstruction of what 'actually happened' (Mishler 1999), as all experiences and memories of the past are inevitably made from a present time and understanding (Riessman 1993, 2008). What was considered as most interesting to analytically explain was how parents talked about what had happened and how they, thus, constructed their understanding of events

and actions in the past, thereby showing what they wanted the listener to know. The (problem-solving) processes created in Study II analysed the parents' individual ways of defining and responding to their children's symptoms. But above all, they also shed light on the shared cultural ways of illness and help-seeking behaviour of the parents (Mishler 1986, 1999), as well as indicating the moral underpinnings of parenthood (Ribbens McCarthy et al. 2000, 2003).

### *Studies III-IV: Narrative accounts enacting and shaping social life*

De Fina (2009) asserts that narrative accounts are based on factual information, structured and organised as events and actions that the people evaluate and make sense of in the process. However, people do not just tell stories, as Czarniawska (1997) has pointed out; stories are above all enacted and as such, narrative accounts provides legitimacy and accountability (to) and for action (Scott & Lyman 1968). In studies III and IV, another definition of narrative accounts offered by Scott & Lyman (1968:46) also guided the analysis, hence acting as "a linguistic device used whenever an action is subjected to evaluative inquiry, or a (enacted, my remark) statement made by a person to explain 'unanticipated or untoward behaviour'."

The parents in this study drew upon different discourse devices to explain and evaluate actions from self and from others, involving the use of linguistic devices for making excuses and/or justifications for parental and story characters' actions and thoughts. Furthermore, parents' accounts carry social meanings and show features of the social world. But narrative accounts also enact social life, and additionally shape the processes (see Pentland 1999) in social life that we aim to study. As social life and parenthood is essentially moral, a parent has to be able to present herself or himself as a 'moral' actor (Goffman 1959). Specifically important for mothers as they are expected, by self and others, to put their children's needs before their own, and because 'good parenting' is particularly interlinked with the mothers identity and moral self in ways they cannot escape (see Ribbens McCarthy et al. 2000; May 2008).

Examples of linguistic and discourse devices used by the parents in Studies III and IV are quotations or footings (Goffman 1981), meaning that parents made references to reported speech of characters in their accounts (also known as double-voicing), for example, healthcare professionals, family members and fictional or impersonalised characters. Other language features used were repetition of words, use of personal pronouns, dialogues, generalisations (as in making use of generalised others, Holdsworth & Morgan 2007), expressive sounds like mimicking a character, used to make a particular point (Riessman 1993, 2008) or to tell a moral tale. All these linguistic and discourse devices were used in different combinations to make moral statements or build moral plots and arguments.

### **An ethical consideration**

The study design in the four studies was approved by an ethical committee at Karolinska Institutet, Stockholm Sweden, during the years 2001-02.

Ethical aspects are important for the whole research process, and one particular aspect that will be considered here relates to the willingness and eagerness of most parents, interviewed for this thesis, to tell their everyday stories.

At the beginning of my contacts with the parents, some mothers were a bit reluctant to be part of the studies because they had previously been engaged in medical studies from Karolinska Institutet, which had meant their children had gone through different testing procedures concerning their allergies. When the nineteen parents were first contacted, two mothers were particularly reluctant, especially when I presented myself as a PhD student coming from Karolinska Institutet. The reluctance had to do with not wanting to put their children through any more invasive procedures. When it was explained to them that I was not a medical professional but a social scientist interested in their experiences as parents, the mothers made an immediate 'response- turn' and expressed a very positive approach in participating. Expressing especially that they had much to share, and how important it was to gain more information about their situation.

Conducting qualitative interviews means engaging in a joint discourse that are in several ways like any other interaction (Mishler 1986). Still, the interviewer has the 'power' of deciding what to ask and of the direction of the interaction, including also control over how the experiences and stories from participants are interpreted, explained and written up later on.

Hence, a significant ethical aspect originates from the understanding that interviews are much like any social interaction, except that the process afterwards is fully controlled by the researcher. Interactions may make people open up (Marshall & Rossman 1999) and narrative interviews are especially suggestive in this sense, as enquires are usually more 'loose' and 'freely' carried out, enhancing the dialogical perspective (Riessman 2008).

Most mothers (and the father too) participating in the studies were very much open about their experiences, including what they had done and their evaluation of their stories, evidently some more than others. Hence, qualitative interviews may have 'the power' to make people talk, which, of course is what is hoped and meant to occur. But this also makes the researcher accountable, for respecting and caring for the trust that interview respondents may give (Kvale 1997). Not only in the obvious sense by protecting their anonymity, but in the sense of having in mind that it is possible that the interview interaction may make people open up more than they actually mean to do so. Hence, they may say things that were not meant for the larger public ear, as in a published thesis.

As such, a few times I had to 'remind' the mothers and myself, usually the mothers whom I connected the most with, about my social role of a researcher. Twice, it seemed particularly necessary to remind the mothers that their experiences would eventually be made public in scientific journals and as part of my dissertation.

In turn, the above is, furthermore, related to how the mothers in this thesis would feel about the interpretations and conclusions made in this thesis, and whether they would feel that they are 'rightfully' represented. But in the end I would argue that it is important that our analysis and explanations of respondent's stories are made 'independent' of them, otherwise we would have a difficult time studying social life



through the use of individual stories and experiences. Besides, as stated before about the 'nature' of interviews, no one 'owns' what is being said in interviews, ensuring that their meanings are constructed in dialogue between respondents and interviewer (Mishler 1986; Riessman 2008).



### 3. Summary of the empirical studies

#### Study I

##### *Allergy-like conditions and healthcare contacts among children with exclusion diet at school*

The aim of the first study was to describe health care contacts and diagnostic testing among school children with exclusion diets, and compare the magnitudes of allergy-like conditions among those children, who had versus those who had not consulted health care professionals for their food-related problems.

Nearly all parents (93%) had consulted health professionals for their child's allergy problems in general, but somewhat less (85%) for specifically food-related symptoms. Sixty-eight children had been doctor-diagnosed with food allergy, most with a positive allergy test. The majority of the children were reported by their parents to have several allergy-like problems and symptoms from many different offending foods and other substances. The findings indicate that 82% of the children had the allergic diseases of asthma, eczema or hay fever, and 53% had reacted to other types of allergenic substances, such as furred animals, pollen and mites.

The children who had seen a doctor regarding their food-related problems had more complex and medically severe allergies than the other children. It was only in this group that the children with breathing difficulties and anaphylaxis were found, indicating more acute and life-threatening symptoms. They also reported significantly more offending food items per child than in the other children and more frequent occurrences of asthma, eczema and pet allergy. However, the characteristics of food-related symptoms and the reported food items in the two groups were similar.

The conclusion of this study is that the children had food-related problems that were consistent with the clinical knowledge of food hypersensitivity, and that they had additional allergy-like conditions and other hypersensitivities that may explain why they needed special diets at school.

#### Study II

##### *Organizing allergy and being a 'good parent'*

In Study II, we focused on the social problem solving processes that those parents, particularly the mothers, engaged in when trying to understand their children's symptoms and problems. One way to understand this process is to analyse the parents' narratives about how they recognise, interpret and respond to their children's bodily problems.

The process of trying to understand their children's problem was constructed by the parents and through the analysis as a process that unfolded over time. The parents narratives consisted of two main temporal phases: (1) the pre-problem phase,

consisting of an awareness of allergy that sometimes led to preventative actions; and (2) the emergence of the child's bodily problems in the everyday situation.

*The constructed pre-problem phase* describes how parents organised their child's allergy, as something that preceded both the birth of the child and the emergence of bodily symptoms. Parents were aware of, ready for and sometimes even expected an illness like an allergy to emerge, and some parents actively tried to counteract this. Given the fact that parents, especially mothers feel responsible for their children's health, emphasising preventative actions made before the child has fallen ill is also a way to justify the moral correctness of parental actions.

The parents constructed the *emergence* of the child's bodily problems in two different ways – in an *acute* and direct way, and in a more *gradual* and drawn-out way. The bodily signs of *acute problems* were more evident and were quickly responded to in terms of allergy and of 'seeking medical aid' – progressively leading to a medical treatment and often an immediate and confirmed allergy diagnosis (like a positive test result pointing to a specific offending allergen). For the parents, the problem-organising pathway was fairly straightforward.

*The gradual problems* had a different and more open pathway. It was possible to outline four main interpretative and responsive strategies for the emergence of these bodily signs: (a) at first, bodily signs were considered and managed as 'normal' infant (child) problems; (b) eventually these signs became recognised as symptoms of illness (allergy, other illnesses), whereby some parents turned to the child health care centre for advice; (c) most parents tried different self-diagnosing and self-treatment strategies; and (d) when these failed (or were only partly successful) and/or a new situation arose, these parents also turned to the child health care centre or sought other medical aid.

Parents had at least two strategies they used to guide them in this process – self-diagnosing techniques in the form of temporal and *situational clues*. Situational clues meant that they either carefully observed any naturally occurring situations when the child was eating something to discover symptoms, or that they experimented with different situations and interactions to try to establish causal links between objects, substances, places and the child's symptoms. Parents often sought medical help after their own methods and strategies had either failed or had only partly or temporarily succeeded in explaining or making the child's symptoms disappear or improve. But an important aspect of their problem solving and decision-making is that it was also formed within a pre-problem context of their moral accountability, and their construction of moral parental self in the interviews. Showing how they had acted in ways that indicated to others that they are 'good parents'.

### Study III

#### *Mothers' accounts of healthcare encounters*

This study explores the mothers' accounts of healthcare encounters and questions about when and how they make claims of moral agency, and is partly a continuing narrative of the problem solving process reconstructed in Study II. Study II shows how parents' understanding of their children's problems are told as being acute and in a

straightforward way or a gradual and drawn out process that guided their help seeking. The way mothers constructed themselves as responsible parents in the problem solving process in Study II is also continued and further emphasised in this study. The specific aim of this study was to show how mothers used the interview situation to present, defend and sustain their identities as 'good' mothers – *when* and *how* they make claims of being responsible parents (moral agency). An additional attempt is to further explain how some of the variations in mothers' experiences of interactions with healthcare, and particularly how mothers' claims of being responsible parents may be formed by their different social belongings, shaping how they come to present themselves in the interview accounts.

The mothers' accounts are constructed as descriptions of what mothers said happened when they sought healthcare help for their children's problems, and how that resulted in two different outcomes: a *quick diagnosis or a drawn-out process with disagreement between health professionals and mothers* (connected with the findings from Study II). Their accounts are about how they experienced these different outcomes and their interactions with healthcare professionals. *The straightforward accounts* were constructed in ways that made healthcare professionals the main narrative agents, who took control over the medical encounter and the children's care, deciding what to do and what was best for the child. When a diagnosis was quickly made and an appropriate remedy given, the mothers also seemed fully content with the medical help they received; both middle and working class backgrounds constructed these kinds of accounts.

In situations of *disagreements*, the mothers use the interview situation to work out what it means to be a responsible mother and/or to present themselves as good mothers. Disagreements between the mothers and healthcare professionals about what was wrong with the child had often led to a drawn out process of diagnosis and these were experienced and accounted for in different ways by mothers, particularly from upper (middle) class and working class mothers, respectively. Healthcare professionals' views and responses, for example, their 'reassuring' statements that nothing was medically wrong with the child and their rejections of mothers' mundane diagnosis and explanations could be depicted by the working-class mothers as salient judgments on their competence as mothers, which they positioned themselves as not being able to disregard.

In the working class *mothers' negotiation of culpability*, health professionals are presented as either 'accomplices in blame', or occasionally as the main 'blame character'. But they also ponder and evaluate their own blameworthiness in the process. As these mothers present their position as dependent on healthcare and their expertise, these mothers' social position is thus potentially more vulnerable in terms of interactions with healthcare, having negative consequences for the mothers' identities. In order to be and to show that they are competent and responsible mothers, they have to also deal with conflicting sociocultural scripts of the passive patient and the assertive mother. In contrast to middle class mothers, the working-class mothers combine different narrative strategies in their work of moral agency, and make seemingly incompatible moral positions appear righteous.

In comparison with the working class mothers, the upper (middle) class, although they told accounts about disagreements with healthcare professionals too, they did not however depict these as judgements of their mothering ability. Upper (middle) class mothers portrayed themselves as especially being self-sufficient and as having full control of the situation in finding the correct diagnosis and remedy for their child, on their own. They constructed themselves as clearly independent of healthcare professionals expertise, and appealed in their accounts to the fulfilment of the *active mother role*, which they were fully at home in. Their creation of moral agency and moral worth as good mothers was less about defending themselves or their actions. It was dominantly about portraying themselves as good competent middle class mothers, who can and do make independent and rational choices in interactions with healthcare and their children's care.

## Study IV

### *Parents' support for an ordinary life*

The objective of this study was to explore parents, mainly mothers, accounts of the practical and discursive strategies they use to support an ordinary life for their allergic child. This includes how they manage family relations, in particular, in their accounts of family responsibility and the way they control the information they give about their child to others.

In parents' support of an ordinary life, they discursively establish the ordinary by making comparisons with others, particularly other (non-allergic) children's everyday life and their own families. This means that their child may as much as possible live a life like that of any other children. What is considered ordinary in daily life is also often accounted for as being self-evident and not something parents usually explain or reflect upon, but presumed that the listener would agree with.

Parents' support is also about practical strategies used to create or uphold an ordinary life for their children. In terms of the children's food problems, there is one particular and dominant strategy the parents use, conceptualised as 'the food-bag strategy', where the child is given his/her special foods to bring when participating in different activities and social gatherings. In living and being like any other child, parents also work to counteract the child being socially excluded, overlooked or looked upon as different (special). In terms of the 'food-bag strategy', the mothers construct it to work in two opposite directions, both for and against their parenting support. Practical strategies may work well for protecting the child from accidental allergic reactions or from getting symptoms of their illness. It may also potentially protect the child momentarily from the possibility of being overlooked and left-without, when their peers are eating something they cannot eat. Still, at other times it may work as an antagonist to the child's ordinary life and identity. It may in fact become the actual social signifier of the child's otherness and difference in relationships with their peers, which most of the time is not a social consequence of the illness, food allergy/intolerance, 'itself'.

Another aspect of parents' support is how to manage family relations; in this study, parents' accounts are mainly explanations and reflections about *family responsibilities*. Specifically, how to legitimise and justify their claims or 'demands' on family members'

understanding and support, and family members' inabilities or unwillingness to do so. There is a clear *moral dimension* in parents' accounts about family responsibility. Reflections and evaluations of what may be socially and morally justifiable to demand from others are intertwined with the parents' examples of the difficulties in making family members understand the child's allergy.

The children's grandparents are put in a special responsibility position compared to other family members. Being able to visit grandparents and family members seems to be a taken for granted part of everyday life. Thus, this may be partly why the kinship ties and responsibilities from children's grandparents, in particular, are those that are mostly exemplified and problematised in the parent's accounts. However, the parents also *downplay family responsibility* and *make legitimate excuses* for family members' actions and behaviours, in and through generally shaped '*moral tales*'. Downplaying family responsibility works to *protect both family members and the parents' own moral self*. Protection of parents' moral self is deemed important so as not to risk being seen as the kind of person that does not respect the needs and choices of others.

A final important strategy the parents use in contact with others is *information control*. Namely, mothers feel compelled to overemphasise the information they give about their child's problems and illness identity to others, on specific occasions, in order to make others understand and to keep the child safe or symptom free. But they try to do so without stigmatising the child in the process, and to not risk turning their child into a situational threat, 'abnormal', 'too special' or a child that others may pity. Information control is said to work, just as the 'food-bag strategy', against the child's 'ordinariness'. The mothers may, therefore, have to simultaneously balance the information they give about who the child is in certain situations and to relations, to *reframe* the child's potentially socially threatening image. An image that parents' previous information may have the unfortunate consequence of creating and mirroring in peers and others.





## 4. Discussion

The aim of this thesis has been to explore the everyday practical and interactional strategies used by mothers in their parenting of children with allergies, in different contexts and relations where their parental self and identity may be at stake. It is chiefly through the mothers' actions that we may understand what parenting children with an allergy may be about. There are five aspects to their actions that have to be considered for an understanding and explanatory framing of specific parenting methods by mothers, and in the broader sense of parenthood, childhood allergy and the social and moral practice of everyday life. These are: (1) Practical strategies that shape lay knowledge of child allergy in everyday life, (2) aspects of gender and the medical encounter and (3) strategies and moral self, (4) the dilemma of parental control and finally (5) the "costs" of overbearing responsibilities.

### *(1) Practical strategies shape lay knowledge of child allergy*

The parents used several practical everyday strategies before they sought healthcare to control, manage and understand their children's problems. They continued to use pragmatic ways of managing everyday life, mainly relating to food allergies, and these ways became important especially when children started school and when they "go out into" the world on their own. Parents' practical strategies are, thus, what seemingly shape much of the everyday knowledge they have of their children's problems. For example, at the time when they first sought medical help, most of the mothers were already convinced that their children's problems were anything but "normal" (own words); some were convinced that it was an allergy.

Additionally significant for how accounts about disagreement with healthcare professionals are constructed and experienced by the mothers' Study III. This may especially count for those mothers who were not content with the responses they got from healthcare professionals, for example, when they were being told by health professionals that "nothing was (medically) wrong" with their child, as their self-diagnosing strategies had already guided them to understand children's problems as a sign of illness (however, not always knowing what illness).

From the findings in Studies II and III, it seems that it is situational explanations that foremost lead to disagreements or lack thereof in the encounters between healthcare professionals and the mothers (see also Voysey 1975). This is why it is important that mothers' everyday strategies and rationales about their children's (emerging) bodily problems, as communicated to healthcare professionals, are considered in the different clinical and healthcare settings (see also Prezant & Marshak 2006) where childcare experts encounter the children and their mothers. I will come back to discussing what implications the above and other findings may also have for childcare practice.

### *(2) Gender and medical encounters*

As was argued in Study III, some mothers may experience reassurances and non-medicalisations of the child's problems by healthcare professionals as silent/tacit judgements on their mothering competence, or the mothers perceived that healthcare

professionals do not listen to them or take their everyday knowledge seriously. The latter may be related to other studies focusing on women's experiences with healthcare encounters (Wiles 1993; Henwood et al. 2003). For example, a study by Wiles (1993) showed that women experience, what they perceive as poor interpersonal behaviour from a doctor, more negatively than do men. Several of these women also expressed, similar to working class mothers in this thesis, how doctors did not take either them (as persons, my remark) or their complaints seriously (Wiles 1993). It seems as if gender may explain this pattern among women. The women in Wiles' (1993) study consisted of mainly upper (middle) and middle class women.

Why it was only working class mothers in Study III that drew on such 'feelings', and not the middle class women, may be explained by what was at stake for the mothers in the interviews, namely, justifying their 'good mothering' and trying to reconstruct moral agency as the working class mothers or appealing to the fulfilment of an active mother role that the middle class mothers were already confidently positioned in. The working class mothers' (narrative) reconstruction of moral agency, and their "having to" restore their moral self (Frank 1997) in their accounts can, furthermore, be linked with Skeggs' (2006) research about class and gender formation among working class women, and their overbearing struggle to become respectable.

### *(3) Strategies and moral self*

A third aspect that could illuminate how parents' practical strategies are interactional is linked with mothering responsibilities for the child's moral self and identity. As in controlling and sometimes also having to reshape the child's self and social image. Unfortunately, the 'food-bag strategy' communicates a social image and a self-image of being a differentiated and special child (the opposite of an ordinary child), something that parents do not want for their child. This also means that the practical strategies work both against and for the parents' intentions.

The parents in this thesis construct parenting strategies as partly being non-negotiable. In supporting their children with allergies, many mothers comprehend their controlling strategies as necessary. It is sometimes the only way in which they may 'control' the uncontrollable aspects in the child's everyday life, for example, other peoples' actions or their everyday living, the natural environment and the workings of social life. Having control in supporting children with food allergies is deemed as highly necessary (because others don't understand!) in order to keep the child safe and healthy in particular social situations that the child may partake in, especially without their parents.

In certain situations, parents may be able to reframe their child's potentially threatening or morally doubtful and stigmatising image that sometimes had been the unfortunate social consequence of their information control to start of with (Study IV). Thus, in some way they may have 'another' chance to redefine the situation.

Food allergy is different from other chronic illnesses in this way because it is precisely the risks from the ordinary socially shared life that threatens the child's health and the child's possibility to live an ordinary life. As stated in the introduction, many children with food allergies do not always have any subjective symptoms and not always any

visible signs of their illness either, which is also the case for other illnesses such as diabetes and epilepsy. Consequently, a chronically ill child may at times be able to 'pass' as being 'healthy'. With allergies, passing as being healthy, however, is connected with whether parents may be able to control that the child does not become exposed to any allergens in contact with others and the outside world.

#### *(4) The dilemma of parental control*

If parents cannot control the outside world, especially other peoples' ways and understanding, how are the children supposed to take part in an ordinary life, in the way their peers do, without risking their health (and in the worst case, their life)? Parenting strategies are aimed at solving this dilemma, but as indicated in Study IV, the strategies that work well in keeping the child safe, work reciprocally to create the social consequences of food allergies at certain times and in certain situations. Nevertheless, these strategies may possibly stigmatise the child in the process of keeping him or her safe, and thus, sometimes create a risk for the child to be socially excluded or separated from their peers and an ordinary child identity.

It is predominantly mothers who try to counteract these potential social consequences of their controlling strategies in any way they possibly can (namely, reframing and balancing the child's socially risky image), although too often, with the materialised 'food-bag strategy' especially, parenting children with allergies sometimes simply means, having to accept the social consequences of their strategies *in favour of keeping the child healthy and safe*. As the anthropologist LeVine (1974) proposed, the basic goal of keeping children alive and healthy is the number one universal goal for parents.

In previous studies on the lived experience and management that focuses foremost on asthma, the main findings show how the children and their parents engage in normalising symptoms and signs of asthma in their everyday lives. Thus, the normalisation process is about concealing, rejecting or distancing ones identity from aspects of ones asthma and allergy that may potentially threaten the 'healthy' and ordinary self (Hansson-Scherman et al. 2002; Prout et al. 1999; Gabe et al. 2002; Hansson 2007).

In contrast to the above, the strategies used in parenting children with food allergies are not aimed to conceal or reject the illness identity of the child. In these instances, to keep the child healthy and safe, the most crucial aspect of mothers' strategies is to make other people aware and understand. Therefore, they have to at times, over emphasise the child's (food) allergy problems and illness identity in different situations, thus, doing the opposite of illness concealment. Making others understand is also crucial for the child's ordinary identity and for the child to be able to live an ordinary life like that of their peers. As such, information control and the 'food-bag strategy' are embedded in an interactional context that shapes what parents in this thesis do, in order to enable their child to have an ordinary life. Thus, their strategies are the opposite of the normalisation process described above, and in the thesis introduction (Radley 1994; Olin Lauritzen 2004; Roll Bennett 2006).

Parents point to other persons' inability to understand children's allergy and individual needs to a general widespread lack of knowledge about allergies. As such, they construct

a quite different social picture of an allergy than what was stated in the thesis introduction, where food allergy is socially communicated as exaggerated and overestimated. It is implied that mostly the media coverage (Shepard 2006), but also other social arenas where food allergies are regularly communicated, for example, the clinical setting (since healthcare professionals are known to over diagnose food allergy/intolerance) have resulted in that individuals and families with children have been 'given too much knowledge' about what may or may not cause allergies and what foods that may be risky for our health, in terms of allergies and other conditions (see Nettleton et al. 2009).

### (5) The "costs" of overbearing responsibilities

It may be argued that what parents attribute to both family members and seemingly other well knowledgeable and informed agents such as childcare experts and healthcare professionals in their inability to understand children's allergies due to lack of knowledge about allergies, may have moral underpinnings too, similar to the many other aspects of being a mother. This was similar to Study IV, whereby not wanting to portray significant others such as family in a way that would make them into unwilling or unsupportive people (Finch & Mason 1993), or childcare experts as 'incompetent'. Since doing so would also imply something about the mothers' parenting responsibilities, that is, not having lived up to their responsibilities, or not showing 'enough' parenting independence. At the same time, it may also imply something about them as persons, as discussed in Study IV. Thus, all of these factors may potentially put both their parental identity and moral self at stake. Additionally, it may be that requiring others to understand would be to overstep social conducts of behaviour and unwritten boundaries of social claims and demands in social relations.

What the parents seem to mean when stating that peoples' lack of knowledge is the reason for them being unable to understand their children's needs and allergy (and this is regardless of social ties and healthcare expertise), is that people simply do not understand what it *means for them as a family (to live with an allergy)*. Hence, the parents cannot require or demand others, not even family, to fully understand what it means for them as a family. Here, parents seemingly make use of the discourse of the independent and 'individual' family unit, whose lives and experiences are in ways separated from that of both close family members, friends and others (see also Kugelberg 1999). However, at the same time, in their accounts about family responsibility in Study II they also show and account for interdependence in everyday life of family responsibilities and relations.

Hence, what is striking in parents' accounts is how they often weave seemingly opposite themes and threads together in their accounts.

One example of the weaving of opposites in this thesis is how parents' accounts show them to both accept and deny, for example, how close family members are able to understand the child's allergy and needs (and take on responsibility). On the one hand, they make legitimate excuses (Scott & Lyman 1968) for the grandparents' inability from the discourse and value of family independence (see also Finch & Mason 1993). But on the other hand, they construct moral tales about social characters' (generalised) behaviours and attitudes that work to represent the inappropriateness of the kind of

behaviour they had previously presented from the family member. Hence, these moral tales indicate certain social expectations that the mothers, in particular, have for close family members, especially the grandparents.

Several other studies focused on mothers' constructions and presentations of being 'good' mothers have found the 'weaving of opposites' in parenting accounts as well, only conceptualised in different ways. What seems to be a common ground in mothers' accounts are how they in different ways appeal to contrasting discourses about certain topics of motherhood; specifically trying to live up to dominant constructions and often competing normative discourses that do not go neatly with their own experiences and demands of everyday life (see for example, Brown et al. 1997; Bell 2004; Miller 2005, 2007; Collett 2005).

Additionally, in dealing with contradictions in dominant constructions of the good mother, presenting a responsible and competent parenting self and moral self, thus, becomes crucial. Another aspect related to this is that of the children's appearance being significant for mothers, for them to maintain a good mother identity and presentation of self (Collett 2005), generally speaking, as well as being able to make specific impressions of a disabled child to pass as competent parents (Voysey 1975). In yet another study of mother's parenting children with autism spectrum disorder, they used different 'mediating practices', which conceptualises similar meanings as mothers' information control, hence, "mothers mediating practices are vital for a formation and maintenance of positive identities for their children and for themselves in the context of the lived experience of disability" (Rocque 2010:345).

The contrasts in the mothers' accounts may be conceptualised as they entwine the opposites of what may be different moral positions because of the way the mothers narratively present themselves and others in relation to these opposites. For example, like the working class mothers in Study III and their way of trying to combine the dominant construction of the assertive and independent mother, with that of being a 'good working class' patient in contact with healthcare professionals.

### **Implications for childcare practices**

Parents' practical and interactional strategies are important in showing what are at stake in parenthood, and in being an especially 'good' parent in the context of everyday life. Everyday life is compounded with principles and ideologies of how to live, how to parent an ill or healthy child, and how to be a social and moral agent. What others think about us, and what we think about ourselves is reciprocally about the same (Mead 1934; Goffman 1959). This is why being a good parent in the eyes of others is crucial for being able to feel and comprehend this to be true, also for ourselves. It is, therefore, inevitable that this has certain implications for childcare practices, in particular, for how childcare experts in different areas such as healthcare, nurseries and the schools that care for children, respond to and meet the children's parents.

For one thing, because food related problems are highly contested (illuminated in the two expressions "true food allergy" and "allergy between the ears"), it also means that mothers will at one time or another encounter attitudes and responses, emanating from these expressions, from others. The fact that the expression "true food allergy" is

seemingly used in healthcare practices (see Nettleton 2009) and additionally, food allergies and food intolerances being difficult to verify and clinically diagnose, the healthcare setting is accordingly a potentially strong interactional context where mothers' moral self and agency are easily threatened.

All of the above taken together may potentially lead to situations where mothers feel their mothering competence may be questioned, especially when they and healthcare professionals have different views about their children's symptoms, as shown in Study III. Additionally, mothers comprehend that they (as the working class mothers did) are dependent on healthcare professionals to fulfil their mothering responsibilities (Murphy 2003).

Hence, if mothers cannot sustain a 'good mothering image' in encounters and interactions with healthcare professionals or any other childcare professionals, and yet are dependent upon them and their expert knowledge in some way (Murphy 2003), this may also affect their self-esteem and self-concept (Stryker 1980).

This may mean, therefore, that if mothers feel like 'bad' mothers in interactions with healthcare professionals or other childcare professionals, this will also have implications for the possibilities for childcare professionals to be able to offer guidance and aid to mothers, at least in ways that are truly supportive and helpful. Hence, professionals working in different childcare practices need to acknowledge the 'moral impact' of social interactions, as their words, behaviours and ways of meeting and talking to the children's mothers may affect mothers role performance and self (Stryker 1980). If the lay/expert relationship and interaction with children's uttermost responsible parents, the mothers results in them feeling they are blamed or judged as irresponsible or incompetent, thus, potentially 'bad' mothers, this will also possibly affect to some extent, the allergic child's care and well being.

## **Methodological considerations**

In concluding this thesis, only two methodological considerations will be discussed even though there are numerous things that may be discussed in terms of how studies have been carried out and analysed. The first is about the link between narratives as a method and narratives as a finding. The second is a brief note about explaining social class from individual narratives.

### **Methods and findings mutually reinforced in narrative accounts**

When studying how parents account for their parenting and what they do to manage their children's allergy, the methodology and empirical findings are intertwined in certain ways, as they mutually reinforce each other. The findings are, thus, a result of the methodological focus of narrative accounts and the way in which parents make use of linguistic and discursive devices to show and explain actions, interactions, events and happenings they built their stories around, in response to and in dialogue with the evaluative enquiries of the research questions put forth by me in the interviews (Scott & Lyman 1968). The focus in this thesis on parents' ways of presenting themselves, their actions and other people and their actions was, thus, both an objective for the different

qualitative studies and the subsequent result (empirical findings). Seemingly a tautology, it is, however, not an analytical mistake, but rather a prerequisite for understanding what parenting an allergic child is all about, as it is not only about what parents say they do. It is as much about how and why the parents say what they do (Riessman 2008), because it is specifically through the parents' interactional and communicative strategies that we gain knowledge about the social and moral imperatives of parenthood and of social life.

As interview accounts are always more or less retrospective and the interview is a discourse between speakers (Mishler 1986), people will create social meanings of their experiences through their talk, and do so by following socially shared conventions of interactions (Atkinson 2009).

### *A note on social class explanation*

As discussed in Study III, disagreements with healthcare professionals as experienced particularly by working class mothers, as salient judgements of their parenting competence was not the case with any of the middle class mothers in this thesis. Still, it should be cautioned when drawing any overall conclusion of social class in terms of the class definitions and small narrative sampling. However, it may still be considered valid in the empirical sense that the narrative constructions of mothers as dependent or independent can explain the variations between the mothers in the study. It seems plausible that these constructions are informed by their social positions, and can also to some extent be substantiated by previous research (see for example, Lupton 1991; 1997).

Study III in this thesis may be comprehended as 'experimental', making an attempt to connect the narrative positioning of individual mothers with social structures on the levels of their social group belonging. The analysis is based on individual narratives and experiences related to patterns between mainly upper (middle) class and working class mothers; therefore, caution should be taken when interpreting the differences only in terms of social group differences. There might be other situational and social aspects that may contribute to the differences, which have not been possible to take into account in the study. Another possibility is that classifications of mothers' social class are too imprecise and one-dimensional for making 'good' class analysis.

To end these reflections, the attempt to connect individual narrativity and moral identity work with that of a particular aspect of a structural perspective of social background is important. As there are no true divisions or contradictions between the social (structure) and the individual (agency) or between the structuring and the contingent aspect of social life. It may be that they become opposites in the everyday lives of individuals, and in parenting accounts, as they work to make sense of children's allergies within a highly individualised social and moral context, which means having to continuously present and construct themselves (and their children) as moral actors and selves, and in the process also having to protect other individuals' rights and ordinary lives (Douglas 1992).

To end with, as Pierre Bourdieu has stated many times, that structure and agency are two sides of the same coin: *"the notion of habitus accounts for the fact that social agents*

*are neither particles of matter determined by external causes, nor little monads guided solely by internal reasons, executing a sort of perfectly rational internal program of action"* (Bourdieu and Wacquant 1992: 136).



## Acknowledgements

My PhD journey started exactly a decade ago. I was a full time PhD student until 2004 when I had to go on sick leave and since then I have primarily carried out my thesis project on a part time basis. My PhD journey has been a contingent path. Over the years I have acquired knowledge and experiences both in terms of my research and of who I am; at my side I have had several people who have played an important role in my journey, both personally and professionally. I would like to thank each of you.

First, I would like to send a special thanks to the *parents* interviewed for this thesis. It has been a privilege to take part in your experiences and listen to your stories. What has touched me the most is the creativity and endurance your words, actions and presentations of yourselves as parents have communicated to me. You have shared with me your strategies of parenting a child with an allergy, in an everyday world where all is contingent and nothing ever certain, and you have still made it work somehow. I hope, my thesis is able to share some of your knowledge to others and to make others perhaps understand better what it means to live everyday life with an allergy; an aspect of your parenting that many of you told me was the “hardest part”.

I would like to give special thanks to my main supervisor, *Lena Borell*. You have been a true pillar and have always stood by my side and (on my side) when things have not always followed the traditional doctoral path. Especially when I have been too independent for my own good. I thank you both personally and professionally as you have supported both sides of me, especially when during the years, they may have coincided a bit too much. As you know, I always tend to do the opposite of ‘making it easy’, and I thank you dearly for putting me back on track and repeatedly endorsing that I can do it. I hope that I have produced a ‘good enough’ result, in the end.

Great thanks also to my other supervisors for your different expertise and support. Special thanks for support with last minute writings. *Lars-Christer Hydén*, as my main co-author and social scientist, your guidance and knowledge, particularly in narrative theory and methodology and the lived everyday experience of illness, has been invaluable to me. Even when it may have seemed that I have not listened enough to your advice. You have been my (nearly only) link to the research world of the social sciences.

Thank you *Helena Hemmingsson* for stepping in during the last three years and especially for making me accountable for the choices I have made, meaning my ‘wild’ independence and how I perform things at the spur of the moment. I thank you especially for your structured and organised supervision, and trying to keep me in line with things, something I truly needed.

*Staffan Ahlstedt*, I thank you for the immense support at the beginning of my thesis project, and for not losing hope in me finishing this thesis. Your allergy expertise and open attitude towards my research far from your own have been important from the very start, especially in making me feel like I belong at Karolinska Institutet and that my research is interesting and important. You are an immaculately thorough supervisor, with an eye for details. You always engage in reading what I send you, not only quickly but also very meticulously. It has been my misfortune that I have not been able to use

your critical and methodical eye on everything I have written.

Professor emeritus *Bengt Björkstén*, for selecting me for the interdisciplinary PhD projects at the Centre for Allergy research. I have always felt your support and belief in me; thank you for your well wishes for me. I was thinking, you know- some people are 'wild geese's', difficult to tame, and some are already tamed-and will never run wild. Thank you!

My 'old' PhD colleagues, *Jennie, Nariman, Pär, Petter, Birgitta, Erik, Cecilia, Pirjo, Tanja and Pernilla*, at the former Centre of allergy research- most of you have written and defended your thesis years ago. I have lagged behind, but here I am! Thanks for particularly the first few years when we had just started and did things together. Special thanks to *Jennie* and *Nariman* for all we shared back then, I miss you!

To you *Cecilia (Cia)*, for being my friend and support whom I have been able to call when certain things just need 'ventilating', a big thanks also goes out to your family, for letting me stay over. Thank you (again) my friend *Birgitta (Bitta)*, for what I thanked you for in my licentiate thesis. In addition, for being a good friend, even after you moved and we unfortunately got to meet so seldom. I miss our everyday chats, and the light in your window and your heart!

I thank all of other PhD student (specifically *Mandana, Lisa, Annika, Sofia and Ingela* for your unique contributions to my journey) researchers and teachers at the division of Occupational Therapy where I have had my workroom for the last ten years. I know I am one of the 'oldies' at the division, but I know I have not been the only one to 'stay forever'. You have all made my place of work the best it possibly can be, I believe. Thanks especially to *Louise Nygård* for arranging readings of papers and for your encouragement in research and teaching. Another special thanks to you *Karin Johansson*, for reading and taking time to discuss my papers as well as other things about the PhD process, especially as a fellow social scientist. *Staffan Josephsson*, for encouraging comments on my work, and letting me know that it is ok to not always take the traditional path. *Agneta Eriksson*, for always being able to answer all my questions, but also for being who you are and for the talks we have had about 'the other parts of life'. Thanks *Malin Lindell* for being patient with me and for everything practical.

*Meena Strömqvist*, my new proofreader, thank God I found you! I don't know what I would have done without your willingness to go out of your way and accommodate me in the 'last minutes' (as sitting here now writing this to send to you). I am so grateful, for that and also for your work. Finally, no more 'swenglish' after editing!

To thank the union negotiator for SULF, *Robert Anderson*, and KI doctoral student representative, *Patriq Fagerstedt*, for taking on my case.

I have been blessed with always having people around me that in different ways have truly been there for me, both in mind and in spirit or present in my life in different ways on a regular basis. There is just not any sharp divide between the professional and the private in this sense. Sometimes, with some of you, the professional have also become private.

This is most true with you *Sandro Campana Wadman*. I have already told you about how important you have been in my work, and for me finishing this dissertation. Still, I would like to thank you officially too; here in the 'book' that you have been part of, not of writing, but mentally producing. Your knowledge and 'fanatics' about the theories of our friend Bourdieu have spurred my engagement in continuing with my research many times. Especially since you can explain complicated theories like no-one else; just a walk in the park (or walk in the mountains for you). You have been such a big part of me, for perhaps my most crucial years as a PhD student and being Me. You are my twin-soul and the love of my life and you are with me and in my heart forever. Words cannot express how much I miss you. Thank you beautiful, I would not 'have made it' without you!

To my dear friends, *Lena, Anna, Åsa*, and *Eva*. Thanks for being there for me and just accepting me for who I am. *Lena*, for just being who you are and for me being able to stop by from time to time when I have craved company. *Anna*, for being able to call you and for supporting me when I needed something in the last minute writing (and thank your boss Ola, for bits and pieces and 'fika'). *Åsa*, for staying with me and making me think of other things and for always being a good friend. Thank you also for your support in 'proofreading' and many supportive phone calls. To you *Eva*, I thank you firstly for your great professional work in reading my thesis manuscript and your comments on the 'writing up' of my research, and for saying it is interesting. Secondly, for everything else between heaven and earth. We have shared a lot, you and I, and we are much alike in many ways. You have supported all my different sides and roles during these years and you now the way we met was not the happiest times in our lives. It has not only been happy times but you have enriched my life in many ways and thanks for being my dear friend with that big heart. Thank you also for 'sleep overs' and all you have helped me with, nothing said nothing forgotten!

To *Magnus and Jenny*, who were the reason I could get started ten years ago. Thanks for letting me come and stay with you. *Magnus*, my friend, for your never-ending support, despite the distance in time and space, and for being a 'rock in crisis'.

My Baravara friends, thanks for our travelled inner journey in 2007, and for memories and emotions still embodied in my heart forever. Special thanks to *Per, Lina, Henning, Maria, Kalle, Satya & Päivi*; above all, for being who you are.

Beautiful *Shubhaa*, you have given me so much and I want to thank you for reminding me about who I truly am, listening to the light in my heart and not the thoughts in my head. I am so grateful to you and *Talib*- for noticing me that day. You have meant the world to me *Shubhaa*, and for being able to finish my dissertation.

This summer I had the luxury of spending two weeks in Ellen Keys house "Strand" at Vättern, together with four fantastic women. I would like to thank all of you for your company and immense support. *Margareta*, our own Ellen Key, your knowledge about Ellen Key was so inspiring. Thank you, for the wonderful evenings we spent in Ellen Keys spirit. Thanks to my fellow comrades, *Katarina, Karin and Lina*. I had the most beautiful time with you. Special thanks to you *Lina*, for new friendship and for letting me come and stay with you in Karlstad and work with my thesis at your room at Karlstad University. Thanks for reading my article and for convincing me that I could make it. I did! Thanks to Ellen Keys foundation for making it possible.

To *Göran Rydén*, for being there, for great many years during my PhD journey. I have realised now what a big help you were in this process, for just regularly being there, every week, the same time (almost) and the same place. I have missed that since I moved. Thank you! I did make it in the end!

Last but not least, there is family. Thanks to my mother *Monica*, you really drive me crazy, but thanks for trying, and although you have not understood what it is I have actually been doing all these years, all the practical things that you have helped us with have been greatly appreciated.

Thanks to Eliza and Per Løchen for everything you have always done for Synne and me.

Big thanks to my beautiful daughter *Synne*; you are always and forever, the light of my life. That is also what your name means, you are the *sun* of my life. I love you more than anything in the world. Thanks for our times at the stables and riding together, giving me something else to think about for a while. Thanks for doing your best to support me during these crazy last few months and forgive me for not having been the most mentally present mother and for being too hard on you and acting crazy when I have been too stressed. At certain times, you have been the mature one of the two of us, and thanks for being the emotionally intelligent girl you are and for keeping me down to earth.

If I have forgotten anyone, many thanks to you too!

My thesis is dedicated to my daughter *Synne* and our (furred) four-legged friends: *Rasmus, Marre, Tussan, Smulan, Dagol* and *Cheyenne*!

*\* The thesis was funded by grants from Anna and Edwin Berger's Foundation, the Kempe-Carlgrenska Fund and Queen Silvia's Jubilee Fond. I would like to offer my thanks for their financial support, having made it possible for me to finish this thesis. Thanks especially to Kempe- Carlgrenska fund\*.*

## References

- Adams, S., Pill, R. & Jones, A. (1997) Mediation, chronic illness and identity: the perspective of people with asthma. *Social Science & Medicine*, 45 pp. 189-201.
- Ahlstedt, S. & Murray, C. S. (2006) In vitro diagnosis of allergy: how to interpret IgE antibody results in clinical practice. *Primary Care Respiratory Journal*, 15 pp. 228-236.
- Asher, M. I. & Weiland, S. K. (1998) The International Study of Asthma and Allergies in Childhood (ISAAC). *Clinical and Experimental Allergy*, 28 (5) pp. 52-66.
- Atkinson, P. (2009) Illness narratives revisited: the failure of narrative reductionism. *Sociological Research Online*, 14 (5) <http://www.socresonline.org.uk/14/5/14.html>
- Baruch, G. (1981) Moral tales: parents' stories of encounters with the health profession. *Sociology of Health and Illness*, 3 (3) pp. 275-295.
- Bell, I.R., Schwartz, G.E., Peterson, J.M., et al., (1993). Symptom and personality profiles of young adults from a college student population with self-reported illness from foods and chemicals. *Journal of the American College of Nutrition*, 12 (6) pp. 693-702.
- Bell, S.E. (2004) Intensive performances of mothering: a sociological perspective. *Qualitative Research*, 4 (1) pp. 45-75.
- Björkstén, B. (2001) The epidemiology of food allergy. *Current Opinion in Allergy & Clinical Immunology*, 1 (3) pp. 225-227.
- Bourdieu, P. (1977) *Outline of a Theory of Practice*. Cambridge and New York: Cambridge University Press.
- Bourdieu, P. & Wacquant, L.J.D. (1992) *An Invitation to Reflexive Sociology*. Chicago: The University of Chicago Press.
- Brown, S., Small, R. & Lumley, J. (1997) Being a 'good mother'. *Journal of Reproductive and Infant Psychology*, 15 (2) pp. 185-200.
- Brugman E., M.J., Spee-van der Wekke A., Beuker R., Radder J., Verloove-Vanhorick S. (1998). Prevalence of self-reported food hypersensitivity among school children in the Netherlands. *European Journal of Clinical Nutrition*, 52 (8) pp. 577-581.
- Bury, M. (1982) Chronic illness as biological disruption. *Sociology of Health and Illness*, 4 (2) pp. 167-182.
- Bury, M. (1991) The sociology of chronic illness: a review of research and prospects. *Sociology of Health and Illness*, 13 (4) pp. 451-468.
- Bury, M. (1997) *Health and Illness in a Changing Society*. London: Routledge.

Charmaz, K. (1993) *Good Days and Bad Days. The Self in Chronic Illness*. Chapel Hill: Rutger University Press.

Clover, A. (2006) Are the dangers of childhood allergy exaggerated? *British Medical Journal*, 333, pp. 494-496.

Collett, J.L. (2005) What kind of mother am I? Impression management and the social construction of motherhood. *Symbolic Interaction*, 28 (3) pp. 327-347.

Conrad, P. (1990) Qualitative research on chronic illness: a commentary on method and conceptual development. *Social Science and Medicine*, 30 (11) pp. 1257-1263.

Czarniawska, B. (1997) *Narrating the organization: Dramas of institutional identity*. Chicago: University of Chicago Press.

De Fina, A. (2009) Narratives in interview – The case of accounts. For an interactional approach to narrative genres. *Narrative Inquiry*, 19 (2) pp. 233-258.

Douglas, M. (1992) *Risk and Blame. Essays in Cultural Theory*. London: Routledge.

Elvin-Nowak, Y. & Thomsson, H. (2001) Motherhood as idea and practice: A discursive understanding of employed mothers in Sweden. *Gender & Society*, 15 (3) pp. 407-428.

Eriksson, B. E. & Qvarsell R. (2003) Om allergier, risker och ansvar. (About allergies, risks and responsibility.) In (Eds.) Sparrman, A., Torell, U. & Åhrén Snickare, E. *Visuella spår. Bilder i kultur- och samhällsanalys*. Pictures in cultural and social analysis.) Lund: studentlitteratur.

Finch, J. (1989) *Family Obligations and Social Change*. Cambridge: Polity Press.

Finch, J. & Mason, J. (1993) *Negotiating Family Responsibilities*. London and New York: Routledge.

Gabe, J., Bury, M. & Ramsay, R. (2002) Living with asthma: the experience of young people at home and at school. *Social Science & Medicine*, 55, pp. 1619-1633.

Goffman, E. (1959) *The Presentation of Self in Everyday Life*. New York, Doubleday.

Goffman, E. (1967) *Interaction Ritual. Essays on Face-to-Face Behavior*. New York: Doubleday.

Goffman, E. (1968) *Stigma: Notes on the Management of Spoiled Identity*. Harmondsworth: Pelican Books.

Goffman, E. (1981) *Forms of Talk*. Philadelphia: University of Pennsylvania Press.

Gunnarsson, N. (2007) *The Discovery and Management of Child Allergy from the Parent Perspective*. Licentiate thesis. Karolinska Institutet. Stockholm: Reproprint AB.

Hansson, K. (2007) I ett andetag. *En kulturanalys av astma som begränsning och möjlighet. (In a breath. A cultural analysis of asthma as limitation and possibility)* Swedish dissertation. Lund: Critical Ethnography Press.

Hansson-Scherman, M., Dahlgren, L.O. & Löwhagen, O. (2002). Refusing to be ill: a longitudinal study of patients' experiences of asthma/allergy. *Disability and Rehabilitation*. 24 (6) pp. 97-307.

Harden, J. (2005) Parenting a young person with mental health problems: temporal disruption and reconstruction. *Sociology of Health and Illness*, 27 (3) pp. 351-71.

Hays, S. (1996) *The Cultural Contradictions of Motherhood*. New Haven and London: Yale University Press.

Hed, J. (1998) *Immunologiska och inflammatoriska mekanismer vid allergiska reaktioner. (Immunological and inflammatory mechanisms in allergic reactions)*. In (Eds.) Foucard, T., Hedlin, G. & Kjellman, M. *Allergi och astma hos barn (Asthma and allergy in children.)* Lund: Draco läkemedel AB.

Henwood F., Whyatt, S., Hart, A., & Smith, J. (2003) "Ignorance is bliss sometimes": constraints on the emergence of the "informed patient" in the changing landscapes of health information. *Sociology of Health & Illness*, 25 (6) pp. 589-607.

Holdsworth, C. and Morgan, D. (2007) Revisiting the generalized other: An exploration. *Sociology*, 41 pp. 401-416.

Hydén, Lars-Christer & Mishler, Elliot G. (1999) Medicine and Language. *Annual Review of Applied Linguistics*, 19, pp. 174-192.

Illi, S., Von Mutius, E., Lau, S., Nickel, R., Niggemann, B., Sommerfeld, C. & Wahn, U. (2001) The pattern of atopic sensitization is associated with the development of asthma in childhood. *Journal of Allergy and Clinical immunology*, 108 pp. 709-714.

James, A. (1993) *Childhood Identities. Self and Social Relationships in the Experience of the Child*. Edinburgh: Edinburgh University Press.

Johansson, S. G., Hourihane, J. O., Bousquet, J., Bruijnzeel-Koomen, C., Deborg, S., Haahtela, T., Kowalski, M.L., Mygind, N., Ring, J., Hage-Hamsten, P. & Wütrich, B. (2001) A revised nomenclature for allergy. An EAACI position statement from the EAACI nomenclature task force. *Allergy*, 56 pp. 813-824.

Knibb, R. C., Armstrong, A., Booth, D. A., et al. (1999) Psychological characteristics of people with perceived food intolerance in a community sample. *Journal of Psychosomatic Research*, 47 (6) pp. 545-554.

Kugelberg, C. (1999) *Perceiving Motherhood and Fatherhood. Swedish Working Parents with Young Children*. Acta Universitatis Upsaliensis. Uppsala Studies in Cultural Anthropology 26. 300 pp. Uppsala, Sweden.

Kvale, S. (1997) *Den kvalitativa forskningsintervjun*. (The qualitative research interview.) Lund: Studentlitteratur.

Larsson, S. (2009) A pluralist view of generalization in qualitative research. *International Journal of Research & Method in Education*, 32, (1) pp. 25-38.

LeVine, R. A. (1974) Parental goals: A cross-cultural view. *Teachers College Record*, 76 (2) pp. 226-239.

Liamputtong, P. (2006). Motherhood and "Moral Career": Discourses of Good Motherhood among Southeast Asian Immigrant Women in Australia. *Qualitative Sociology*, 29(1) pp. 25-53.

Lupton, D., Donaldson, C. and Lloyd, P. (1991) Caveat emptor or blissful ignorance? Patients and the consumerism ethos. *Social Science & Medicine*, 33 (5) pp. 559-68.

Lupton, D. (1997) Consumerism, reflexivity and the medical encounter. *Social Science and Medicine*, 45 (3) pp. 373-81.

Marklund, B., Ahlstedt, S. & Nordström, G. (2004) Health-related quality of life among adolescents with allergy-like conditions – with emphasis on food hypersensitivity. *Health and Quality of Life Outcomes*, 2 (65).

Marshall, C. & Rossman, G.B. (1999) *Designing Qualitative Research*. 3<sup>rd</sup> Edition. California: Sage Publication.

May, V. (2008) On being a "Good" mother: The moral presentation of self in written life stories. *Sociology*, 42(3) pp. 470-486.

Mead, G. H. (1934) *Mind, Self, and Society*. Chicago: University of Chicago Press.

Miller, T. (2005) *Making Sense of Motherhood. A Narrative Approach*. Cambridge: Cambridge University Press.

Miller, T. (2007) 'Is this what motherhood is all about?': Weaving experiences and discourses through transition to first-time motherhood. *Gender & Society*, 21 pp. 337-358.

Michailakis, D. & Schirmer, N. (2010) Agents of their health? How the Swedish welfare state introduces expectations of individual responsibility. *Sociology of Health and Illness*, 32 (6) pp. 930-947.

Mishler, E. G. (1986) *Research Interviewing. Context and Narrative*. Cambridge: Harvard University Press.

Mishler, E. G. (1984) *The Discourse of Medicine. Dialectics of Medical Interviews*. New Jersey: Ablex Publishing Corporation.



Mishler, E. G. (1995) Models of narrative analysis: A typology. *Journal of Narrative and Life History*, 5 (2) pp. 87-123.

Mishler, E. G. (1999) *Storylines. Craft Artist's Narratives of Identity*. Cambridge: Harvard University Press.

Moneret-Vautrin, D.A., Morisset, M., Flabbee, J., Beaudouin, E. & Kanny, G. (2005) Epidemiology of life-threatening and lethal anaphylaxis: a review. *Allergy*, 60 (4) pp. 443-451.

Murphy, E. (2003) Expertise and forms of knowledge in the government of families. *The Sociological Review*, 51 (4) pp. 433-462.

Nettleton, S., Woods, B., Burrows, R. & Kerr, A. (2009) Food allergy and food intolerance: towards a sociological agenda. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 13 (6) pp. 647-664.

Nicolaou, N., Poorafshar, M., Murray C., Simpson A., Winell, H., Kerry, G., Härlin, A., Woodcock, A., Ahlstedt S. & Custovic A. (2010) Allergy or tolerance in children sensitized to peanut: Prevalence and differentiation using component-resolved diagnostics. *Journal of Allergy and Clinical Immunology*, 125 (1) pp. 191-197.

Olin Lauritzen, S. (2004) Lay voices on allergic conditions in children: parents' narratives and the negotiation of a diagnosis. *Social Science & Medicine*, 58 (7) pp. 1299-1308.

Patton, M. Q. (1990) *Qualitative Evaluation and Research Methods*. California, Sage Publications Inc.

Pentland, B. T. (1999) Building process theory with narrative: from description to explanation. *The Academy of Management Review*, 24 (4) pp. 711-724.

Prezant, P. & Marshak, L. (2006) Helpful actions seen through the eyes of parents of children with disabilities. *Disability and Society*, 21 (1) pp. 31-45.

Prout, A., Hayes, L. & Gelder, L. (1999) Medicines and the maintenance of ordinariness in the household management of childhood asthma. *Sociology of Health & Illness*, 21 (2) pp. 137-162.

Radley, A. (1994) *Making Sense of Illness. The Social Psychology of Health and Disease*. London, Sage.

Ribbens McCarthy, J., Edwards, R. and Gillies, V. (2000) Moral tales of the child and the adult: Narratives of contemporary family lives under changing circumstances. *Sociology*, 34 (4) pp. 785-803.

Ribbens McCarthy, J., Edwards, R. & Gillies, V. (2003) *Making Families: Moral Tales of Parenting and Step-Parenting*. Durham: Sociology Press.

Riessman, K. C. (1993) *Narrative analysis*. California: Sage Publications, Inc.

Riessman, K. C. (2008) *Narrative Methods for the Human Sciences*. California: Sage Publications.

Rosengren, K-E. & Arvidson, P. (1992) *Sociologisk metodik (sociological methodology)*. Fjärde upplagan (fourth edition). Falköping: Almqvist & Wiksell Förlag, AB.

Rocque, B. (2010) Mediating self-hood: exploring the construction of maintenance of identity by mothers of children labelled with autism spectrum disorders. *Disability & Society*, 25 (4) pp 485-497.

Roll Bennet, P. (2006) *Föräldraskapande och barnets hälsa. Föreställningar och berättande om barn med eksem*. (Parental creating and children's health. Ideas and narration about children with eczema), Swedish Dissertation. Pedagogiska institutionen, Stockholms universitet.

Rose, N. & Miller, P. (1992) 'Political power beyond the state'. *British Journal of Sociology*, 43 (2) pp. 173-205.

Rudestam, K., Brown, P., Zarcadoolas, C. & Mansell, C. (2004) Children's asthma experiences and the importance of place. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 8 (4) pp. 423-444.

Sachs, L. (1997) *Vårdens etnografi: om hälsa, sjukdom och vård i sitt kulturella sammanhang*. Lund: Liber förlag.

Sampson, H. A. (1999) Food allergy. Part 1: Immunopathogenesis and clinical disorders. *Journal of Allergy and Clinical Immunology*, 103, (5) part 1, pp. 717-728.

Sampson, H. A. (2004). Update on food allergy. *Current Reviews of Allergy and Clinical Immunology*, 113 pp. 805-19.

Sayer, A. (2005) *The Moral Significance of Class*. Cambridge: Cambridge University Press.

Scott, M. B & Lyman, S.M. (1968) "Accounts". *American Sociological Review*, 32 pp. 32-46

Shepard, R. (2006) *Allergy between the ears?* In Gilissen, L.J.E.J.; Wichers, H.J.; Savelkoul, H.F.J.; Bogers, R.J. (Eds.) *Allergy Matters: New Approaches to Allergy Prevention and Management*, vol. 10, pp. 205 Softcover.

Sicherer, S. H. (2002) Food allergy. *The Lancet*, 360 pp. 701-10.

Skeggs, B. (2006) *Att bli respektabel. Konstruktioner av klass och kön*. (Formations of Class and Gender. Becoming Respectable). Uddevalla, Daidalos.

Spergel, J. & Pawlowski, N. (2002) Food allergy: Mechanisms, diagnosis, and management in children. *Pediatric Clinics of North American*, 49 pp. 73-95.

Stryker, S. (1980) *Symbolic Interactionism: A Social Structural Version*. Menlo Park: Benjamin Cummings.

Sundelin, C. (Eds.). (2000) The importance of the Child Health Services to the Health of Children. *Acta Pædiatrica. An International Journal of Paediatrics*, 89, supplement 434, pp. 1-80.

Tulloch, J. & Lupton, D. (2003) *Risk and Everyday Life*. New Delhi, Sage Publications.

Voysey, M. (1975) *A Constant Burden. The Constitution of Family Life*. London: Routledge and Kegan Paul.

Wahn, U. (2000) What drives the allergic march? *Allergy*, 55, pp. 591-599.

Wickman, M. & Lilja, G. (2003) Today, one child in four has an on-going allergic disease in Europe. What will the situation be tomorrow? *Allergy*, 58 pp. 570-571.

Wiles, R. (1993) Women and private medicine. *Sociology of Health & Illness*, 15 (1) pp. 68-85.

